

Health Literacy Project, Phase 1:
Needs Assessment of the Health Education and
Information Needs of Hard-to-Reach Patients

Part 2

**Report on the Needs Assessment at the
Montreal General Hospital**



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Odette Langlais, an educational consultant, carried out the research under the guidance of the Steering Committee, with unmatched thoroughness and dedication. She forged strong relationships with all the patients she met, and showed great patience of her own during the entire revision process. She was assisted by co-researcher Claire Elliot, librarian at The Centre for Literacy in drafting the Background Paper on Health Literacy (please see Preface), and by consultant Charles Draper in conducting the interviews and focus groups. Ms. Langlais drafted both the Background Paper and the Needs Assessment with feedback from the Steering Committee, and later, from the external evaluator.

As requested by the Research and Ethics Committee of the Montreal General Hospital, a report by an external reviewer was prepared. Dr. William Ninacs, chairperson, *Coopérative de consultation en développement La Clé*, served as the evaluator. The Research and Ethics Committee approved the Needs Assessment Research Plan in March 2001. Dr. Ninacs accepted to serve as a resource person/external evaluator beginning in May 2001, after the data collection had been completed.

Dr. Linda Shohet edited both final documents, the Background Document on Literacy and Health and The Needs Assessment Report.

Nursing staff on Dialysis, Oncology Hematology and the Pre-Operative Centre, the three hospital units that participated in this study gave unstintingly of their time and support, despite the perpetually stressful conditions in the medical system. The 114 informants who participated in interviews, focus groups and physician response also showed great generosity, the patients often in the face of extreme medical circumstances. The study could not have taken place without their cooperation and input. Health Canada also worked closely with the Steering Committee throughout the process. Their framework for continuous evaluation is a model of excellent funding practice.

The Steering Committee has approved the content and recommendations of the Needs Assessment Report. This report is dedicated to the patients, caregivers, support staff and health care workers who collaborated with us on this study, and to those whose needs we hope to meet through the recommendations we propose.

Executive Summary

Background

The Montreal General Hospital, McGill University Health Centre (MUHC)¹ is a large downtown teaching hospital located in Montreal. A large proportion of its patient population is multicultural. Many patients do not speak English or French as a first language, and many of them are low-literate. As a bilingual teaching hospital affiliated with a major medical school, it situates itself on the cutting edge of research and as a leader in the field of university medical teaching. The Montreal General Hospital is committed to providing the highest possible quality of healthcare.

These characteristics set the stage for the hospital's initial involvement in health literacy in 1995. It began when the Director of Nursing Staff Development attended a conference on health literacy and recognized that this issue affected many patients at the hospital. First steps included a series of professional development workshops on health literacy for health care professionals between 1997 and 1999, the product of a partnership between The Centre for Literacy of Québec and the Montreal General Hospital. Since then, the Department of Nursing Staff Development has sustained a continuing interest in health literacy. Hospital staff are aware that the changing nature of healthcare has led to a growing number of patients having to take care of themselves at home; many of these patients are potentially incapable of doing so because they have difficulties reading, understanding and applying health information received at the hospital.

In 2000, a Health Literacy Steering Committee was set up in collaboration with The Centre for Literacy to launch a major initiative on Health Literacy. They developed the concept for a proposed Patient Health Literacy Centre to address the communication needs of low-literate patients. A two-phase study was designed. Phase 1 included a literature review/background paper on literacy and health with descriptions of all related projects in Canada, and a needs assessment of the situation at the MGH. After the literature review was completed, the concept of "low-literate" was changed to "hard-to-reach" to reflect recognition that communication barriers could have diverse causes, of which low literacy was one. The Needs Assessment was to identify the precise nature of the local problem and to propose some solutions. The Committee foresaw that the results of the Assessment would guide the development of a pilot Health Literacy Centre² in a subsequent Phase.

This report presents the findings from the Needs Assessment. The research project is described in Section 1. Details of the Research Plan are in Appendix 2, and the concerns expressed by the external reviewer and the Research Ethics Committee can be found Appendix 4. Section 2 presents the results, and Section 3 gives the recommendations for the pilot Health Education Centres.

¹ Since the first involvement of the Montreal General Hospital, the hospital has become integrated into the McGill University Health Centre (MUHC), an amalgamation of four large downtown teaching hospitals. They have been merged into one organization prior to relocating to a single site scheduled to open in 2005. The outcomes of the project are shared with the planning committee of this new facility.

² This is the term initially used by Committee members. As explained at the beginning of Section 3, the term evolved and was changed to "Health Education Centre."

Rationale

The 1994 International Adult Literacy Survey (IALS) informs us that nearly half the population of adult Canadians has some degree of difficulty with everyday reading materials. This has serious consequences for the health of Canadian citizens since everyone needs to understand and use information on health and health care at some point in their lives. Low-literate patients face health information, materials and procedures that are difficult or impossible for them to understand and apply. But there are other groups of patients with whom it is also difficult for health care professionals to communicate effectively. These “hard-to-reach” patients include those who face language and cultural barriers, and those who have difficulties processing health information because of physical or cognitive disabilities. This study started by asking, “What can be done to improve health education and information for hard-to-reach patients at the Montreal General Hospital (MUHC)?”

Purpose of the study:

- a. To determine the health information and health education needs of hard-to-reach patients at the Montreal General hospital (MUHC).
- b. To formulate recommendations for the creation of a Health Literacy Centre to improve the communication of health information and education for this group of patients.

Methodology:

A qualitative methodology was chosen because of the nature of the research. Data was collected through 66 individual interviews and 7 focus groups with four groups of informants—hard-to-reach patients, members of their families, support staff and health care workers—from three units of the Montreal General Hospital (MUHC)—Dialysis, Oncology Hematology and the Pre-operative Centre (45 participants in total). The individual interviews included health care workers from two affiliated community health clinics (CLSCs). Physicians from the three hospital units were asked to comment on a synopsis of the results.

Some key findings

The health information needs of informants

- Patients identified their primary needs as medical information about the illness; information about daily living: diet, exercise, activity level; and teaching about tests and taking medication.
- Family members/caregivers want to know about the patient’s feelings, about coping with the illness, about impact on family life, and about health resources in the community.
- Health care professionals believe these patients need disease-specific information, better-adapted teaching material, and an improved teaching process. They also believe that there is a core group who probably do not understand the health information currently given to them, and some who will be difficult to reach under any circumstances.

Methods of communication currently used to inform and educate patients

- A majority of patients found that the written documents given in each unit are not directly useful to them, because they have a language barrier, or because they do not read and their caregiver does the reading for them. However, a significant number (40%) did find them useful.
- A majority of patients were dissatisfied with the oral communication with medical staff.
- Few patients receive health information from sources other than written documents and oral communication. The only other source cited by a significant number was videos.
- Learning with computers was not a popular option among patient interviewees.

The needs of health care professionals as educators of hard-to-reach patients

- Health care professionals need more time to assess the literacy and comprehension level of patients, and to teach hard-to-reach patients; written material available in languages other than English or French; and more posters and health videos to show and to lend.
- Health care professionals need more money allocated for translation, plain language writing, training health care workers and buying videos and visual materials.

What health care professionals know about health literacy

- Informants had a general idea of what low literacy means, but few could describe low-literate patients or clearly define health literacy.
- Many health care professionals worry about patient comprehension and how to validate their teaching.

Ideas on the Health Education Centres

- Patients said an Education Centre should be attached to each unit in a clearly marked, easily accessible room, and should house all the pertinent information/services.
- Health care professionals would like the Health Education Centres to offer training on aspects of health literacy.

Analysis

The patients interviewed had been identified as hard-to-reach by nursing staff. However, they did agree to the interview or to participation in a focus group, which indicates that they were reachable when approached individually and accorded time and attention. Most of the health care workers felt that there is a core group of patients that is harder to reach than those with whom we met. Care-givers often play a major role as listeners and readers for these patients, and health care providers rely on that. Patients and providers differed in their assessment of patient needs. Patients expressed a need for information and good teaching, but also wanted respect and sensitivity to their concerns. While health care workers spoke about empowering patients, most of them tended to focus on giving information and validating teaching. All groups saw the possibility of health education centres filling some of these diverse needs. Like any cross-section of the population, hard-to-reach patients are hard-to-reach for different reasons; they may be low-literate, speak another language, be traumatized by lives in war-torn countries, have a physical or cognitive disability, or belong to a cultural community other than

the two mainstream ones. These sub-groups have different ways of learning. One of the most provocative findings was that most of these patients do not, and do not want to, use computers. As many Canadian hospitals and health care centres are increasingly relying on computer-mediated information systems for patients, this finding is critical. The recommendations for the health education centres have followed from these and other findings and analysis in the report.

Summary of Recommendations

1. *One pilot Health Education Centre should be set up in each participating unit.*
2. *A **health care professional** should be responsible for coordination on a part-time basis.*
3. ***Volunteers**, including former patients, should be available to staff the Centres and be involved in programming, under the supervision of the coordinator.*
4. ***Patients and families** who use the information services of the Centre, and participate in the programs and activities, should be involved in evaluating them.*
5. *An **Education Committee**, composed of a patient representative from the unit, a family representative from the unit, the health care professional in the position of co-ordinator, a representative from the Health Literacy Steering Committee, and possibly a volunteer and a support staff member, should oversee each pilot Centre.*
6. *Groups, composed of patients, families and health care professionals in each unit, should develop their own guiding principles and hypotheses, using the present report as a starting point. The Education Committees could facilitate these group processes.*
7. *The **Health Literacy Steering Committee**, as the driving force behind the entire project, should assume a co-ordinating and research management role for all three pilot Centres.*
8. *The Centres should develop **multi-faceted approaches** to patient information and activities, and offer different kinds of health information to meet the different needs of patients and caregivers.*
9. *Computers and computer-based education should not be a preferred option in the short-term.*
10. *Financial resources should be allocated in order to research, borrow, adapt, reproduce or produce, if necessary, written material and videos offering basic health information in Italian, Greek, Spanish, Cree, and possibly other languages to be identified.*
11. *A **professional development training program** for health care workers should be designed.*
12. ***Participatory group activities** should be planned with patients and caregivers.*
13. *The Centres should offer a friendly, welcoming atmosphere free of stress and anxiety.*
14. *The first visit to the Centres should become part of the intake and orientation process for new patients.*
15. *Special steps should be taken to accommodate hard-to-reach patients who may be hesitant to use such Centres.*
16. *A system should be developed so those patients who go to the Centres do not lose their "place in line" (if there is one) for their treatment or appointment.*

Section 1. Description of the Needs Assessment

Rationale

The 1994 International Adult Literacy Survey (IALS) informs us that nearly half the population of adult Canadians has some degree of difficulty with everyday reading materials. This has serious consequences for the health of Canadian citizens since everyone needs to understand and use information on health and health care at some point in their lives. Low-literate patients face health information, materials and procedures that are difficult or impossible for them to understand and apply. This can have a negative impact on their health. IALS findings corroborated other studies that have shown a correlation among poverty, literacy and health. But there are also other groups of patients with whom it is difficult for health care professionals to communicate effectively, both in writing and orally. These “hard-to-reach” patients include those who face language and cultural barriers and those who have difficulties processing health information because of physical or cognitive disabilities. For these patients, health information and education are often communicated in ways that they cannot understand and that are not useful to them. It is difficult for them to get answers to their questions.

Health literacy has been defined by researchers in the field as: “The ability to use written materials to function in health care settings and to maintain one’s health and the skills needed to advocate for and request needed clarification.”³ As a prior step to conducting this Needs Assessment, a Background Document on Literacy and Health⁴ was developed. It became apparent that the term “health literacy” is not widely used in medical settings and that few health literacy programs exist in Canadian hospitals. Steering Committee members became aware that their work was breaking new ground in Canada, looking at patient education from a new point of view, and members wanted to investigate more than the “ability to use written materials.” They also wanted to look at the capacity of hard-to-reach patients to understand and use health information transmitted orally by health care workers, health information included in videos, as well as information from other sources (visual materials, workshops, patient discussions groups, etc.). Could these other sources of information and education processes complement and/or replace written information as a useful source of health information for hard-to-reach patients?

More specifically, what could be done to improve patient education for hard-to-reach patients at the Montreal General Hospital (MUHC)? What are the health education needs of hard-to-reach patients and their families here? And what are the needs of health care professionals as educators? The first step was to talk to those who face the challenges of giving and trying to understand medical information on a daily basis in the hospital: patients and their caregivers, health care workers and support staff. Because no comparable models of patient education for

³ From Rudd, Rima E. and Barbara Moeykens, Adult educators’ perceptions of health issues and topics in adult basic education programs. National Center for the Study of Adult Learning and Literacy (NCSALL), US Department of Education, report No.8, August 1999, p.1.

⁴ This document can be accessed through the homepage of The Centre for Literacy of Québec (www.nald.ca/litcent.htm) under the title Health Literacy Centre Background Paper, May 2001. It gives an overview of key issues and practices, and descriptions of health literacy initiatives in Canada.

this target group exist in Canadian hospitals, it was necessary to begin with a Needs Assessment.

Methodology

Since there was no model of comparable research, Steering Committee members knew that the research would be exploratory. It was not possible to support or refute claims about the needs of hard-to-reach patients, looking at large numbers of patients as such data did not exist. Committee members, therefore, decided to use a small sample of informants and focus on “issues” rather than “numbers.” They knew that the data collection would encompass many uncontrollable variables, and that findings would require significant interpretation, further arguments for choosing a qualitative rather than a quantitative methodology. A qualitative methodology was chosen as most appropriate considering the nature of the research. We did eventually interview 66 individuals, talk to a further 45 in focus groups, and receive feedback from 3 physicians.

Committee members decided that it was important to include the views of physicians, but planning individual interviews and focus groups with physicians was difficult because of time constraints. It was decided to ask a physician from each of the three units to comment on summary of the findings from the Needs Assessment. Three physicians submitted written comments that have been integrated into Sections 2 and 3 of this report where appropriate. Because their responses were written, it is possible to quote them directly. All other feedback is paraphrased or summarized by the researcher from her notes and observations. Committee members gave feedback to the initial drafts.

Choosing the participating units and informant groups

Committee members wanted to work with hospital units that care for large numbers of patients and where patients (and/or their families) need to be involved in ongoing self-care at home. Patients from these units need a lot of health information and education; health care professionals take significant time to teach these patients and their families; and patients and families are generally “hungry” for relevant information. In response to a request through the Nursing Staff Development Department, three units expressed interest in participating in the Needs Assessment. The three were Dialysis, Oncology Hematology (outpatient department), and the Pre-operative Centre (hereafter called Pre-Op). In two of the three units (Dialysis and Oncology Hematology), patients face a chronic health problem and are likely to receive medical care for many years. This would facilitate the tracking of patients to evaluate over time the impact of alternative patient education methodologies in a subsequent phase of this project.

Committee members chose four groups of informants to provide diverse perspectives: These were hard-to-reach patients themselves, their families or caregivers, support staff, and health care professionals. Patients and health care professionals are directly involved in the patient education process. Committee members knew that for many patients, the family plays an important role in providing care and processing information, particularly for patients facing a

chronic illness. They also knew from the literature review⁵ that the role of support staff in dealing with hard-to-reach patients was frequently overlooked. The limited research that exists suggests that hard-to-reach patients may possibly be more at ease with support staff and find them more approachable than health care professionals, if they have questions.

As part of the approval process, the Research and Ethics Committee of the Montreal General Hospital (MUHC) requested a report by an external reviewer who raised some concerns about the design. The Steering Committee made a number of adjustments, including creating a consent form that met the criteria of the hospital, but was also in language plain enough to be understood by the target group patients. [See Appendix 3 for the final version of the Consent Form and Appendix 4 for a description of the concerns and the adjustments]. The Needs Assessment Research Plan was evaluated and approved by this Committee on March 14, 2001.

Design of the data collection instruments

Committee members and the principal researcher decided on individual interviews and focus groups with the four identified groups of informants. They did not want to give out written questionnaires (an obvious problem for low-literate patients) but preferred to facilitate a dialogue with informants through individual interviews with the principal researcher and a co-researcher.

They wanted to provide the opportunity to develop a relationship with informants in a relaxed informal environment. Answers were therefore gathered through a conversation-dialogue rather than a rigid question-and-answer format. The researchers encouraged informants to “go off on tangents,” go into depth on specific health-related issues, and feel free to express needs and provide other information not necessarily part of the questionnaires. The researchers wrote responses and detailed notes on the questionnaire forms, but chose not to record any sessions.

The rationale for holding several (7) focus groups was to give informants the opportunity to share their views with peers, to participate in a group dynamic and to develop a collective sense of group identity and empowerment, and possibly a collective position on certain issues. Everyone who participated signed an Informed Consent. Researchers read the form to patients and caregivers.

The approach was inclusive and participatory, in keeping with the Committee’s philosophy that this approach underlies the most effective practice in both patient education and staff training (and adult education in general). Focus groups were open to all who wanted to participate. Informants in individual and group interviews had many opportunities to contribute, i.e. “tell their story,” offer solutions, express a point of view and share opinions with peers.

⁵ Please refer to Section 2.7 *The role of support staff* in the Background Document on Literacy and Health.

Limitations

From the beginning, the Committee was conscious of the limitations of this study. The question of how to identify hard-to-reach patients was a variable difficult to control. Nursing staff from each unit were asked to help identify those patients they felt were hard-to-reach, using a set of indicators developed by the Committee. These were derived from the literature and from the experience of Committee members most of whom were health care professionals. The indicators included: Lack of fluency in both English and French; obvious cultural barriers; socio-economic background; general difficulties in reading and understanding information (e.g. patients who repeat the same questions, or return repeatedly with the same issues, or those who might have a blank look during information sessions); obvious learning difficulties due to cognitive or physical disabilities; education level, if such information was available. Nurses were asked to use any written documentation they had or their own observations of behaviour to identify potential informants. As the group of patient informants was relatively small (51, including 35 individual interviewees and 16 focus group participants), and only three hospital units participated, generalizations cannot be made across the entire health care sector. Nevertheless, the total number of informants (114) provided a rich source of data, and the Steering Committee feels that the findings confirm some hypotheses, call some into question, and give rise to others, laying the ground for further investigation. The findings come at a particularly opportune time for the Canadian health care system when studies are suggesting that medical error is more widespread than previously believed. How much of this error might be attributable to a lack of effective communication with hard-to-reach patients?

Based on the findings of this study and on the literature review, the researchers and the Steering Committee have formulated hypotheses about the information and education needs of hard-to-reach patients that have been transformed into the recommendations for the pilot Health Education Centres in Section 3.3.

Benefits of health literacy: Quality of life, potential saving to the system.

Members of the Steering Committee and others involved at the hospital want to improve the capacity of hard-to-reach patients to learn about their health and become more involved in their self-care. For patients, this capacity can enhance their quality of life. But there are other positive impacts of improved patient education. One health care professional interviewed individually made the link to savings for the health care system and better quality of family life:

"If there is better communication, then these patients will be less anxious. This will mean fewer medical complications for them. This will lead in turn to lower costs for the system in general, and fewer family problems for the patients themselves."

Lower costs are a convincing argument for many decision-makers and health care administrators.

Section 2. Results of the Needs Assessment

The more informed we are, the less stressed we are. It is like finding yourself in a forest with many roads. When we receive the information we need, the roads are illuminated, and we can choose the best one.

(A comment by a caregiver. Translated from French.)

The sample

Individual **interviews** of 30 to 60 minutes were conducted with 66 individuals, from three different hospital units and two area CLSCs, with the following distribution:

| | Dialysis | Oncology Hematology | Pre-Op Centre | Other (CLSC) | TOTAL |
|-----------------------------|----------|---------------------|---------------|--------------|-----------|
| Patients | 19 | 8 | 8 | | 35 |
| Caregivers | 1 | 4 | 5 | | 10 |
| Support Staff | 3 | 2 | 1 | | 6 |
| Health Care Workers* | 4 | 3 | 4 | 4 | 15 |

* The health care workers included nurses, dietitians, social workers, and one pharmacist.

7 focus groups, lasting 45 to 60 minutes, were then conducted with a total of 45 participants. One focus group was held for each of the following groups: Dialysis patients; Dialysis nurses; Oncology Hematology patients; Oncology Hematology caregivers; Oncology Hematology nurses; and health care professionals from the Patient Education Sub-committee of PQIC (Practice and Quality Improvement Council).

| | Dialysis | Oncology Hematology | PQIC | TOTAL |
|----------------------------------|----------|---------------------|------|-----------|
| Patients | 8 | 8 | | 16 |
| Caregivers | 1 | 7 | | 8 |
| Nurses | 8 | 7 | | 15 |
| Health Care Professionals | | | 6* | 6 |
| TOTAL | 17 | 22 | 6 | 45 |

* This number includes one nursing librarian from the professional quality committee.

Gender

The gender breakdown of participants was as follows:

| | Patients | Caregivers* | Support Staff | Health Care Workers |
|---------------|-----------------|--------------------|----------------------|----------------------------|
| Male | 23 (66%) | 5 (50%) | 4 (66%) | 2 (13%) |
| Female | 12 (34%) | 5 (50%) | 2 (34%) | 13 (87%) |

* Of the 10 caregivers, 5 were male (of these, two were husbands and three sons of patients) and 5 female (including four spouses and one patient's daughter).

The data does not reflect our initial intention to interview men and women in relatively equal numbers. This was flagged during the course of the data collection. The hard-to-reach patients identified for us were two-thirds men. This may warrant further investigation. Are there more men than women in this group? Do women mask their difficulties more? Are there gender-based social skills involved in the process of getting health information? We know that a higher proportion of hard-to-reach patients are found among seniors. Among caregivers, four out of five older caregivers are female spouses of male patients. Two-thirds of the health care workers interviewed were nurses, and since women dominate the nursing profession, this explains the gender imbalance in this group.

Language

Of the 35 patients interviewed, 11(31%) identified English as their first language, 6 (17%) identified French and 18 (51%) identified Other.⁶

Age

The average age of the patients interviewed was 63. This reflects the fact that there is a higher proportion of hard-to-reach patients among seniors. It also reflects a high average age for all patients in the Dialysis and Oncology Hematology units. According to hospital lists on a particular date in April, the average age of a sample of 37 Oncology Hematology patients was 61. Support staff and health care workers are, by contrast, relatively young.⁷

FINDINGS AND ANALYSIS

The sub-sections below each present a summary of findings followed by analysis. Results from the four groups of informants are always presented in the following order: patients, caregivers, support staff, health care professionals. Sub-section 2.4 presents information on a theme discussed only by patients. Sub-sections 2.5 and 2.6 present results from questions answered only by health care professionals. Sub-sections 2.7 and 2.8 do not follow the same format, but they present additional observations and feedback that deepen the findings.

⁶ See Appendix 6. *Numbers and demographic breakdown* for specific figures.

⁷ Ibid.

- 2.1 General health information needs of hard-to-reach patients
- 2.2 Methods of communication
- 2.3 Input on the Health Education Centre
- 2.4 How hard-to-reach patients like to learn
- 2.5 The needs of health care professionals as educators
- 2.6 The training needs and challenges of health care professionals
- 2.7 Further comments on the focus groups
- 2.8 Some specific challenges of patient teaching

Detailed findings and percentages of responses to questions can be found in Appendices 5-8.

- Appendix 5: Questionnaires
- Appendix 6: Numbers and demographic breakdown
- Appendix 7: Findings from individual interviews
- Appendix 8: Findings from focus groups

2.1 General health information needs of hard-to-reach patients

FINDINGS

Patients

Patient responses can be grouped into three clusters:

1. The large majority of patients interviewed answered that they need medical information about the illness; information about daily living: diet, exercise, activity level, etc.; and teaching about how to take medication and about tests.
2. A minority answered that they need information about how they might feel, how to cope, how the illness could change their life, or information about health sites in the community.
3. A smaller minority answered that they need information about how the illness has changed family life; help to fill out forms; or information about how to get around the hospital.

Dialysis patients in the focus group also identified the need for services. They expressed their need for information and education, but also the need for respect and recognition of their rights as patients. Oncology Hematology patients in the focus group also identified the need for services. This group of patients wants more information to help them make informed choices. They want to be actively involved in their treatment and post-treatment.

Only three patients said the hospital signs were not clear enough; a large majority of patients interviewed think that hospital signs are clear, and hospital navigation was not a concern.

Additional needs:

Patients identified other needs such as information on different options, hazards, treatments, symptoms, side effects and long-term risks; information in other languages, e.g. Spanish and Cree; and more patient-to-patient information transfer.

One dialysis patient indicated the need for *all* dialysis patients to receive basic information and teaching about dialysis. Currently, only those patients who attend the pre-dialysis workshop receive this information. Many patients arrive in Dialysis following an emergency and skip the workshop. Also, patients need this information repeated later on with clear examples. Families need the same information as patients in order to be able to support them. Patients in Dialysis have a lot of time to learn, since they are usually on dialysis for many years. Hence, there are many opportunities to teach them and repeat key information.

Caregivers

Caregivers identified as most important the same three needs as patients: the need for medical information, for information about daily living and for teaching about how to take medication, tests, etc. However, a larger proportion of caregivers than patients identified the need to know about how the patient feels and can cope with the illness, how the illness can affect family life and where to find health resources in the community.

The focus group with Oncology Hematology caregivers confirmed the need for family members to know more about health care resources in their communities, and to know more about how families can deal with the illness. These caregivers were interested in having more and better written information. They did not think that their family members would want to learn with and from other patients.

Support staff

Support staff emphasized the human needs of patients: the need to be welcomed and respected, the need for positive communication and the need for caring medical staff who listen to them. They also reflected on the practical needs of patients, such as the need for family members to help them and the need for basic information to be repeated. They told us that offering more and better-written information to patients would not be the solution.

Health care professionals

Health care professionals believe that hard-to-reach patients need disease-specific information, better-adapted teaching material and handouts, and a better, more thorough teaching process. Health care professionals from the Pre-Op Centre added that there was an urgent need to update written material given to patients.

The majority of health care professionals believe that the information given to patients is simple and easy to understand. But a majority of the same health care professionals also believe that many hard-to-reach patients do not understand it. They said that some patients

manage with the help of interpreters and family members, or with the support of health care workers who simplify the information, etc. Even then, there remains a core group of patients who probably still does not understand the information given to them.

Health care professionals disagreed on whether the health information given to hard-to-reach patients helps them become more involved in their health care and make more informed choices. (half said yes, half said no). If patients cannot understand the information given, it cannot help them become more active participants in their healthcare. It was agreed that the ultimate goal is to have patients become more involved in their health care.

One Pre-Op nurse outlined what she felt should be done to update, correct and rewrite all documents in plain language. She recommended that a body, composed of full-time staff members such as nurses, clerks and education consultants, be set up and made responsible for the collection and rewriting all patient pamphlets and handouts. These professionals should proof read all the material and test it for user-friendliness. Pre-Op staff nurses, she said, have no time to do this.

ANALYSIS

Since a larger proportion of caregivers than patients identified the need to know about the patient's feeling and ability to cope, about how the illness affects family life and where to find health resources, this seems to indicate that health information needs may be different for caregivers than they are for patients. Caregivers probably need to know as much as possible about how to care for the patient, often a family member whose everyday life is directly affected by his or her illness. They also need to know where to find support in the community. It follows that health education centres should have different types of information tailored to the specific needs of both patients and caregivers. One member of the Steering Committee noted several times that in her experience some caregivers of hard-to-reach patients may also be hard-to-reach, and face challenges in understanding the health information. This was corroborated by other Committee members. Since participation in this study was voluntary, caregivers who chose to participate were generally able to communicate quite effectively. However, in trying to meet the needs of hard-to-reach patients in the pilot projects, the possibility of encountering the same problem with caregivers would need to be taken into consideration.

Support staff, more than any other group of informants, emphasized the human needs of patients, the need to be listened to and respected. The literature on health literacy suggests that the role of support staff is often overlooked. This is unfortunate since they can contribute an important perspective. From our findings, it appears that support staff see the issues of patient education and hard-to-reach patients from a different angle. Unlike medical staff, they are not directly responsible for the healthcare of patients. However, they are often on the front line of service and can establish a rapport with patients. Our findings seem to indicate that while support staff are not directly involved in patient education, their perspective is valuable, and should be taken into consideration.

Regarding navigation in the hospital, the literature tells us that this issue can sometimes be a serious problem for hard-to-reach patients. But it did not appear to be the case for the patients interviewed at the Montreal General Hospital (MUHC). However, several interviewees as well as Steering Committee members pointed out navigation problems in other downtown hospitals, such as the Royal Victoria Hospital.

Regarding filling out hospital forms, although the literature reveals that this can be a problem for hard-to-reach patients, it was not identified as a problem by interviewees. There may be particular reasons for this. The Dialysis and Oncology Hematology units have no forms to fill out. However, patients at the Pre-operative Centre do need to fill out the *Admission Data Base*. Four of the eight Pre-op patients interviewed said they needed help to fill out the form, but nurses at the Pre-operative Centre currently answer this need. Help with filling out hospital forms is either not a need for most of the interviewees, or a need that is currently handled by medical staff or caregivers. This may require further investigation. Navigation and forms may pose a problem for hard-to-reach patients in other units, or the strategies developed in the three sample units may serve as models.

Given the open or implicit agreement among health care professionals that there is probably a group of patients who do not understand the information given to them, some specific steps to address this problem should be taken.

2.2 Methods of communication

This section groups informants' responses to questions about written information, oral communication and other sources of health information.

FINDINGS

Written information

More than half the patients interviewed found that the written documents received were not directly useful to them (See Appendix 7). The most common reasons given were that they could not read them because of a language barrier, or that they did not read and that their caregiver took care of the reading. Some dialysis patients had not received the written document. However, a significant group (40%) found that the written documents received in each unit were useful. They said they were clear and that they used them as references, although many said they were not complete. Very few patients criticised the specific information in the written documents. No one commented on the language level, the layout or the design of the written documents. A large proportion of interviewed **caregivers** found the written information very useful and complete.

Oral communication

A majority of patients interviewed were not satisfied with the oral communication with medical staff. This group of patients identified the following problems:

- Language barriers: nurses and doctors cannot communicate in the patient's language;
- Lack of time for oral communication;
- Lack of specific/complete explanations or contradictory information.

However, a significant group of **patients** said they were satisfied with the oral information provided by doctors, nurses and other health care professionals. They said they got answers to their questions.

Overall, interviewed patients commented on three aspects of oral communication. They commented on the “what” or the content of the health information given orally by medical staff; they wanted complete health information and an effective education process. They commented on “how” information should be transmitted; and finally, they expressed the need for a positive human relationship with the medical staff based on two-way communication and respect. They gave some specific advice to doctors, nurses and other health care professionals to improve oral communication (See Appendix 7). One interviewed patient noted that nurses and doctors are always keen to tell patients what to do and to inform them about what they are not doing right. This patient said that nurses and doctors should also know when to congratulate a patient for what he/she is doing right.

A larger proportion of interviewed **caregivers** than interviewed patients were satisfied with the oral communication.

Other sources of health information: videos, group discussions with other patients, workshops, TV and radio shows

Among interviewed **patients**, few have received health information from sources other than written documents and oral communication by medical staff. The only other source of information experienced by a significant proportion of patients is health videos. Videos are shown during the pre-dialysis clinic and at the Pre-operative Centre. Interviewed patients generally found the videos useful and a good source of information. Videos were not useful to blind patients or to patients who face a language barrier.

Very few interviewed patients have participated in group discussions with other patients but many of them thought they would be useful. They made positive comments, such as that you learn a lot from your peers, that you learn from their questions and their testimonies, and that talking to another patient is comforting. An informal group of Dialysis patients currently meets before treatment to discuss health issues as well as socialize. Only one patient had attended a workshop in a CLSC. A few patients stated their preference for learning in the hospital as opposed to a CLSC because of convenience. Generally, patients are not used to other ways of learning about health care, such as group discussions and health workshops.

Some patients listen to radio or television health shows. A large proportion of patients who answered this question do get health information from television and radio shows, but the content is general and rarely deals with their specific health problem.

Caregivers gave similar responses to those of patients. Some interviewees had seen videos and found them useful. One caregiver had participated in a group discussion; none had

participated in a workshop, and while some have seen TV health shows, they did not find them directly useful. Like patients, interviewed caregivers were generally not familiar with other sources of health information.

ANALYSIS

A higher proportion of caregivers than patients found the current written information useful. A probable explanation is that since many interviewed hard-to-reach patients do not or cannot read (more than half do not find the written information useful), the reading becomes the responsibility of caregivers. It is thus logical that a higher proportion of caregivers than patients would find it useful.

A larger proportion of interviewed caregivers than interviewed patients are satisfied with the oral communication. Caregivers appear to play the role of “listener and reader” for the patient, compensating for what the patient is unable to read or understand on his or her own. Caregivers frequently commented on their positive relationship with nurses. Nurses appear to “use” caregivers to reach out to hard-to-reach patients and to make sure that someone caring for the patient knows and understands the essential health care information. The key role of caregivers appears to be recognised and valued by nurses. Many nurses who participated in individual interviews commented on the central role of caregivers in the education process of hard-to-reach patients. This probably contributes to the apparently positive relationship between nurses and caregivers. The role of caregivers in the education process of hard-to-reach patients appears to be very important. It follows that health education centres should take this into consideration when promoting the centre and planning programs and activities. As noted earlier, findings seem to indicate that health information needs may be different for caregivers than they are for patients.

How patients perceive their education process

Some interviewed patients noted the positive impact of health information and education:

- One patient said that it is better to have medical information early rather than later to prevent problems caused by not knowing.
- One patient said it is good to have basic information as complete as possible from the start.
- For one patient, information meant hope.
- One patient said: "The more knowledge you have, the more often you get it, the better."
- A caregiver said: "Knowing more leads to less anxiety."

On the other hand, some patients were less interested in learning about their health:

- One patient said: "If it does not help me to get better, I do not want to hear it. I trust the specialists."
- One patient, said that he does not want to be reminded he is sick, he wants to forget, to take it out of his mind. He only wants limited information : "The less I know, the better I feel."

A note on an intervention at the Dialysis Unit

The Dialysis Unit has been working for many months creating a *Dialysis Patient Education Booklet* that meets some of the needs identified by nurses and patients. A nurse and the social worker are involved in the production. While it has not been written specifically for hard-to-reach patients, the creators have attempted to include appropriate information in plain language and to use a design suitable for hard-to-reach patients. This Booklet should be available in 2001.

2.3 Input on the Health Education Centres

FINDINGS

Patients said they would like to engage in the following activities in a Health Education Centre: watch health videos; read more and better-written information; use computer programs; participate in patient group discussions; and follow small classes.

Patients said the Health Education Centre should be very close to the unit and easily accessible in a clearly allocated room where they can go while awaiting their treatment. All the information/services should be available in that one place. Patients commented on the respective roles of health care professionals, volunteers and patients/families in the centre (See Appendix 7). Oncology patients in the focus group made a number of suggestions, including emphasizing the aspect of prevention and the use of videos.

A small number of interviewed patients said they would not want to use the Health Education Centre. Caregivers confirmed this. Some prefer to learn on their own while others prefer not to learn more about their illness.

Learning with computers was not a popular option among this group of patients. While it ranked as the third most popular option for an activity at the Centre, this is misleading since not all the patients answered this question. In fact, few patients (26%) actually chose computers as a preferred activity. Even when we explained that volunteers could be present in the Health Education Centre to help and guide them, the large majority of interviewed patients did not express interest. Findings from another question revealed that few interviewed patients use computers (17%), and even among those who do, few research health issues.

Caregivers said that patients would like, in descending order, videos, patient group discussions, more and better written information, small classes and computer programs. Their choices paralleled those of interviewed patients in three categories, but they ranked patient group discussions as more popular and computer programs as least. Caregivers confirmed that some patients would not use a centre. They did not comment on the location of the centre, its staffing arrangements or other aspects.

Support staff members offered concrete ideas to improve patient education and suggested activities for the Health Education Centre.

Support staff members had varied opinions regarding computer programs (some think it is a good idea, others do not), but all agreed that drama with hard-to-reach patients is not a good idea. However, one informant thought that drama would work well with Cree patients.

Health care professionals suggested the following activities and programs for the Health Education Centre: Health videos; computer programs; training for health care professionals; more and better-written information; patient group discussion; and small classes.

Computer programs are seen as more appropriate and small classes as less appropriate by interviewed health care professionals than by interviewed patients, caregivers and support staff. Nurses from the Oncology Hematology unit see the need for a Health Education Centre and appear ready to set it up on a short-term basis. They gave specific advice on how to do this. Nurses do not perceive the Health Education Centre as an add-on component, but as an essential element of the patient's care and treatment at the unit.

ANALYSIS

Results show that interviewed patients want to learn in many different ways in a Health Education Centre. There is not one preferred way of learning or one preferred educational activity. This suggests that a variety of pedagogical methods and instruments will have to be used in the Health Education Centres.

Since a larger proportion of interviewed health care professionals than interviewed patients are computer literate, it may explain why they see computers as a more appropriate tool for patient education. There appears to be a gap between the perspective of health care professionals and what hard-to-reach patients told researchers. The literature suggests that many hospitals are installing computer-based patient centres on the assumption that all patients can and wish to learn in this way; the findings from this study suggest that this assumption may be open to question. They seem to indicate that health care professionals need a better understanding of the reality faced by hard-to-reach patients and of their learning needs. Professional development training in the Health Education Centres could address this issue.

A small number of patients said they would not want to use the Health Education Centre. For some of them, it might reflect a feeling of negation about their illness, the reasoning being something like "If I do not think or learn about my illness, I will forget that I am sick". It might also reflect a refusal to become involved. One patient said he trusted the specialists and that his health is their hands. It appears that, no matter how "user-friendly" it is, we can expect that some patients will not want to come to a Health Education Centre. Hopefully, this initial reaction will change over time, after positive comments about the Centre are shared among patients and families.

While some patients might refuse to come, some others might also hesitate. Health care workers noted that those patients who already know the most would probably be the first ones to come. Hard-to-reach patients are used to facing many challenges when learning about their health, and will not be expecting activities, learning tools and strategies tailored to their needs.

It will probably be a challenge to convince them that these centres have been designed for them. When promoting and planning the Health Education Centres, specific strategies should be devised to attract hard-to-reach patients.

2.4 How hard-to-reach patients like to learn

FINDINGS

Interviewed **patients** like to learn in many different ways. Their most popular choices are listening to oral presentations, one-to-one dialogues with educators and watching videos. (Numbers do not add up to 100% because respondents could choose more than one answer.)

| | |
|---|------------|
| Verbal explanations from a health care worker | 94% |
| Learning one-to-one with a teacher (e.g., nurse, doctor, or other health care worker) | 85% |
| Watching videos | 70% |
| Reading | 66% |
| Learning in a group with other patients | 65% |

To learn about health, 16 (45%) patients prefer to be in the hospital, while 13 (37%) patients prefer to be at home. Other patients prefer to be in a CLSC, in their northern community or elsewhere. While the majority do not prefer to be in the hospital, it is the single most common preferred location for learning. Interviewed patients said that they are comfortable in the hospital, that it is convenient, and that that they can concentrate on learning while at the hospital.

Patients gave many answers to the question: *What makes a good teacher?* (See Appendix 7). The answers can be grouped into four large categories: someone who is qualified and knows his or her subject; someone who is a good communicator and listener; someone who values positive human relationships and someone who is empathetic and can relate to subjects outside his/her field of expertise (the qualities of a good pedagogue).

Many dialysis patients are blind or have serious eyesight problems. This has obvious impact on appropriate kinds of information/education. Out of 126 Dialysis patients on the unit list for a particular day in April, 11 were blind or had very bad eyesight, according to the unit nurse. Sight impaired patients in the focus group indicated patient discussion groups as a preferred way to learn.

The focus group held with Oncology Hematology patients lead us to believe that even among patients who were not perceived to be hard-to-reach and who are more likely to read than hard-to-reach patients, the computer is not an attractive medium for learning. This confirms findings about computer programs discussed in section 2.3.

ANALYSIS

Findings reveal that like any cross-section of the population, hard-to-reach patients have many different styles and preferences for learning. Hard-to-reach patients include a large proportion of low-literate people who are not comfortable with written material and computers. The fact that 6 out of the 8 Dialysis patients who participated in the focus group were blind or almost blind led to atypical results regarding the usefulness of written material, computer programs and videos. But overall, the findings indicate that hard-to-reach patients prefer to watch, listen and engage in dialogue and group exchanges, rather than read or use computers.

A majority of patients seem to like learning with health care workers on a one-to-one basis. This has serious implications for staffing since this can be both time-consuming and costly. Health Education Centres should take this into account but try to slowly introduce and increase the importance of group learning processes which are also popular among interviewed patients, are less costly and, according to the literature, hold a lot of potential. Building a volunteer component with retired medical staff is another possible strategy. It is logical that patients who opt to participate in a focus group meeting would be attracted to learning through patient discussions. This seems to indicate that for some patients, (and the group of Dialysis patients was composed almost entirely of hard-to-reach patients) learning through group processes is a popular option. The Health Education Centres should capitalize on this.

The findings suggest that location is an important factor to consider in health education. The hospital appears to be a convenient place for learning. Patients prefer to learn in a place where they have time to think and ask questions.

Looking at the answers to the question *What makes a good teacher?* one can hypothesize that hard-to-reach patients especially need good teachers who offer a balance between knowledge and expertise about health on the one hand, and teaching skills and human qualities on the other.

2.5 Needs of health care professionals as educators of hard-to-reach patients

FINDINGS

Health care professionals spoke of the need to have written material available in the languages spoken by the largest numbers of patients. The issue of producing documents in other languages triggered questions from health care professionals, such as whether it would be realistic and worthwhile to translate documents into additional languages. Some interviewed health care professionals said that only basic health information should be translated.

The majority of informants indicated that more time is needed to assess the literacy and comprehension level of patients and teach hard-to-reach patients. Some health care professionals raised the issue of the additional human resources needed to improve patient education. They asked “Who has the time for all of this?” and “Will resources be provided for additional staff?”

Health care professionals identified two items that they need the most as teaching tools, posters and videos (to show on site and to lend to patients). Dialysis nurses who participated in the focus group saw a need for expertise in the production of posters, videos, etc. One physician said that simple diagrams should be used more often to replace long instructions and gave the example of wordless emergency cards used in planes as an interesting model. Interviewed health care professionals identified the need for the administration to allocate more financial resources to translation, plain language writing, training health care workers and buying videos and visual materials.

The focus group with six members of the Practice and Quality Improvement Council (PQIC) Sub-Committee on Patient Education discussed in particular the need to upgrade and improve written material for all patients. This is a priority of the Sub-Committee. They insisted on the need to hire professional researchers, writers and translators. They said that nurses should not be expected to write in plain language, to translate, to design pamphlets etc. This are not trained for this and do not have the time. Participants in this focus group said that nurses and other health care workers should be trained in plain language oral communication rather than plain language writing. Participants concluded that ideally, health care workers should have a large spectrum of teaching tools, information, and ways to communicate with patients: written information, oral communication, videos, visual information, etc. in order to meet the different needs and learning styles of patients. The health educator should pick what is most appropriate for the patient or family member. However, the current priority of the Sub-Committee is to update and re-write the written information given to patients and families.

ANALYSIS

The majority of informants indicated that more time is needed to assess the literacy and comprehension level and teach hard-to-reach patients. The Health Education Centres would provide both information and health education services, and it follows that more human resources would need to be allocated to patient education.

More visual materials, updated written documents in plain language and more health videos appear to be important needs for health care professionals, but these people do not have the time to look for these materials nor the skills to produce them. Other specialists (i.e. education consultants, video producers, plain language experts etc.) will have to be involved, at least partly, in searching for, adapting and/or producing these types of documents and teaching tools.

The need for human and financial resources to implement these initiatives is a fundamental issue given the current shortages of both in hospitals. It appears that human and financial resources from outside the hospital need to be identified to support, at least partly and initially, the pilot Health Education Centres.

2.6 The training needs and challenges of health care educators

FINDINGS

Health care professionals discussed what they knew about health literacy and low-literate patients. Among the interviewees, no one was ignorant of the issue or unaware that they face low-literate patients in their work. Informants had a general idea of what low literacy means but few could give a complete description of low-literate patients or demonstrate a clear understanding of health literacy. During individual interviews, informants generally described low-literate patients in two ways: how they try to hide the fact that they do not read; or their characteristics such as age, socio-economic level, ways of expressing themselves, etc.

Dialysis nurses in the focus group made recommendations that applied to all patients, not especially hard-to-reach patients. One doctor commented on the challenge of identifying hard-to-reach patients:

“There are probably more hard-to-reach patients than one might suspect. Messages often don’t get across because of unsuspected mental illnesses (e.g. depressed, substance abuse, anxiety disorders...) or personality disorders or quirks (e.g. technicians who are uncomfortable interacting with people).”

The health care professionals collectively added to a list of communication and teaching strategies used with hard-to-reach patients (See Appendix 8). However, many informants gave only one or two strategies, and did not elaborate.

Many health care professionals expressed worry about patient comprehension and how to validate their teaching. They are not sure that hard-to-reach patients or clients really understand what they need to. Nurses said that sometimes it is absolutely crucial for patients to understand the self-care information. Some informants seemed unsure about how to check that the key information is actually understood. For one of the interviewed nurses, the crux of this issue is that health care professionals take for granted that patients have understood the health information. Nurses emphasized the need for more repetition, more follow-up and more validation to make sure that the information is indeed understood by patients. One doctor insisted on the need for repetition and review:

“Doctors try to adapt the way they present information to the intellectual and emotional capacity of patients to absorb information. I find that patients do not retain the vast majority of the information that is presented to them and that it is necessary to review at follow-up visits.”

Many informants were interested in having training on health literacy.

ANALYSIS

It appeared difficult for interviewed health care professionals to formulate a portrait of hard-to-reach patients, how to assess their learning needs and what are appropriate teaching strategies. Because they find it hard to identify hard-to-reach patients, especially low-literate patients, it seemed difficult for some nurses to reflect on the specific information and

education needs of these patients, as opposed to all patients. Since many also appeared worried about patient comprehension and are unsure about how to validate their teaching, it appears that this may be an important “hole” in the patient education process. Health care professionals generally focused on the need for up-dated documents, better teaching tools, resources for translation, etc. They expressed less of a need for improving their own understanding of the reality of hard-to-reach patients and how to better communicate and teach them. On the other hand, interviewed patients did express the need for better oral communication and the need for respect and being listened to by doctors and nurses. These findings alert us to some training needs of health care workers

Since many professionals had “a piece of the puzzle” but few had a full picture, using participatory training processes could facilitate the sharing of knowledge about health literacy and appropriate strategies. The literature reveals that this is generally a more effective way to teach and train adults. It follows that the Health Education Centres should consider such an approach. The Centres could offer training that focuses on how to interact with hard-to-reach patients, and how to validate health education with these patients.

2.7 Further comments on the focus groups

This sub-section offers findings and analysis of issues that arose in the focus groups but did not fit under sub-sections 2.1 to 2.6.

FINDINGS

Dialysis and Oncology Hematology **health care professionals** who participated in focus groups identified many specific elements of information and education needed by patients and by themselves as educators (See Appendix 8). Oncology Hematology nurses were concerned about reaching out more effectively to hard-to-reach patients. They reflected on their daily experience with such patients and identified strategies to improve patient education, such as doing the teaching a week before the first treatment and having primary care nurses assigned to patients. Oncology Hematology nurses pointed out that there is a need to look at the different approaches used by pharmacists and nurses to inform and teach patients. Issues such as timing, who should say what and what is more appropriate should be examined. Adjustments should be made to better coordinate the interventions of pharmacists and nurses.

In the Dialysis unit, nurses work in either home dialysis or hemo-dialysis. Home dialysis patients are treating themselves at home, following an intensive education and training process led by home dialysis nurses. The self-care ratio is very high. Hemo-dialysis patients come to the unit for their treatment three times a week and are treated by nurses and nephrologists. The self-care ratio is lower. For all dialysis patients, diet and fluid intake are crucial issues. Home dialysis nurses are very concerned with patient education and sensitive to appropriate teaching methodologies. They are continually improving the patient education process, exploring new and better strategies. They have effectively taught hard-to-reach patients who are now able to treat themselves at home.

ANALYSIS

4 out of the 8 Dialysis **patients** present at the focus group were hard-to-reach sight-impaired patients and one was Spanish-speaking. The fact that such a high proportion of hard-to-reach patients came to this focus group may possibly reflect a more pressing need among this group for information and education. A few family members were also present. These patients and caregivers seemed very comfortable and caring with one another. Compared to the other focus groups (with health care professionals, caregivers and oncology patients), this group seemed to form a community. Patients seemed to identify as a group with specific needs, distinct from the rest of the health care system, i.e. nurses, doctors, the hospital administration, etc., and seemed conscious of their rights as patients.

It appears that this group of dialysis patients/caregivers has the potential to develop an even stronger sense of group identity and empowerment. The literature notes that the process of developing a sense of community among adult learners or patients takes time. These Dialysis patients have been going to the clinic for years. The specific context of care in a dialysis clinic favours the building of strong ties between patients and caregivers over many years. A few family members are also part of this community. The literature reveals that increased patient participation and empowerment are a desired process and outcome in the field of health literacy⁸. Patients learn that they can understand their health problems, find solutions with their peers and realize that they can change their lives and their communities in a positive way. This empowerment process could be further developed by holding patient discussion groups and other participatory activities and programs with patients and family members at the Health Education Centres.

In answering the question on their needs as educators, Dialysis **health care professionals** seemed more comfortable with the “what” (what kind of information to give and teach so that patients can better manage their health and be effectively involved in their self-care) than the “how” (appropriate teaching methods, how to reach hard-to-reach patients). This points to the need to support nurses so they can apply health education in their daily practice and increase their capacity to identify and answer the needs of hard-to-reach patients.

2.8 Some specific challenges of patient teaching

This section captures some observations made during interviews that add depth to the understanding of the issue. They are not presented as findings and not subjected to analysis.

One health care professional noted that the Dialysis patient population in general is older, passive and difficult to reach. Patients ask for a lot, listen more or less and often have a compliance problem. The family is often present at the start of treatment to take care of

⁸ Please refer to section 2.4 *Discrimination and learner/patient empowerment* of the Background Document on Literacy and Health. According to an article referred to in this section, field research has documented better physical and behavioural health outcomes from increasing participation and control in one’s life.

transport and other logistics, but then disappears, and nurses do not see them anymore. Many families remain ignorant of the patient's treatment, which seriously limits the information and education process of hard-to-reach patients. After treatment, patients are in a hurry to leave the hospital and return home, where often little awaits them. According to this informant, the challenge is to break the passivity of patients in general and increase their motivation to learn and become involved.

Oncology Hematology patients face other barriers to learning: high anxiety and information overload. A lot of the teaching by nurses is done on the first day of treatment when patients are generally not in a good frame of mind for learning. Information overload is also a problem. Too many different health care professionals, medical specialists, nurses, pharmacists, all give out a lot of information on that same day.

In all three units, health care workers are trying to inform and teach seniors who have memory problems, lack concentration, have weak eyesight, or can be passive and/or too anxious to learn.

The CLSC Côte-des-Neiges takes in clients who are poor, without health insurance, illegal immigrants, refugees, unaccompanied children who arrive in Canada with nothing, pregnant women "visiting" Canada, etc. These clients suffer from post-traumatic syndrome, panic attacks and high stress levels. They are often frightened of being refused by immigration authorities and expelled from Canada. Their priorities are staying in Canada, eating and finding money. Health is not a priority; these clients are not in a mental state to learn about health. Low compliance is a problem. If a patient experiences side effects, he or she often stops the medication. According to health care workers, it is a challenge to inform and teach these clients.

Many clients at both CLSCs are afraid of illness and do not want to participate in prevention programs (e.g. screening for breast cancer). According to interviewed health care workers, some have a low motivation to learn. Pre-natal classes have a high dropout rate. Clients are often not comfortable in a group. It is hard to attract them to information sessions or workshops. However, these are more attractive if offered in their language, with an interpreter. Invitations at large in the community do not work. Medical staff must develop relationships with clients and then invite them to information sessions. Also patients can be approached through their ethnic community.

It is a challenge for health care professionals to teach and validate their teaching when patients face a serious language or cultural barrier, when the patient cannot communicate or when the patient gives little or no feedback. Medical staff are not always aware that hard-to-reach patients are afraid and hesitant to ask questions. In some cases, these patients do not want to bother nurses. They believe that their question might be about something that has already been explained. Interviewed health care workers say that the key is to keep in contact with the patient and develop a strong human relationship. Building trust with hard-to-reach patients is very important, and you gain trust over time.

Section 3. Recommendations for the pilot Health Education Centres

The recommendations regarding the Health Education Centres have been derived from the results of the Needs Assessment as well as from the Background Document on Literacy and Health.

This initiative is based on the belief that by being better informed and educated about their health and self-care, hard-to-reach patients and their families will become more involved as active participants in their health care and make more informed choices. This will contribute to improved self-care and better health. As this group of patients draws heavily on the health care system, the outcomes of this project also hold promise as a way of reducing system costs, as well as increasing quality of life.

3.1 Terminology

The initial proposal for Phase I used the term “Health Literacy Centre.” We now recommend that the term “Health Education Centres” be used instead because:

- Using the term “Literacy Centres” would not be a good strategy to attract patients and family members. There is a stigma attached to the term “literacy,” and in French, the term “alphabétisation” carries an even greater stigma. This problem has long been acknowledged in the literacy community.
- Using the term “Patient Education Centres” seems to exclude families. The Needs Assessment confirmed the critical role played by families in the education process of hard-to-reach patients. It is recommended that the Centres target hard-to-reach patients *and* their families.
- The plural term “Centres” reflects the finding from the Needs Assessment that patients and families do not want one single Health Education Centre for the hospital. They want decentralised centres, i.e. one centre per unit.

Definition of terms

- **Hard-to-reach patients** include low-literate patients, patients who face language or cultural barriers and patients with learning difficulties due to cognitive or physical disabilities.
- **Health information** includes all the information given to patients in written form (pamphlets, hand-outs, booklets, etc.), through oral communication or by other means such as health videos, visual documents, etc.
- **Health education** refers to the process by which health care workers facilitate the learning of patients and their families about health. This learning process involves being able to understand and use the health information.

3.2 Rationale, goal and objectives of Phase 2

Rationale

The Health Education Centres will serve as pilot projects to test the effectiveness of selected information and education strategies identified by the Needs Assessment.

Goal

The goal of the Health Education Centres is to improve the health information given to and the health education of hard-to-reach patients and their families.

Objectives

1. To offer appropriate and effective health information and education to hard-to-reach patients and their families. Our target group is composed of hard-to-reach patients and their families. However, the Centres will be open to all patients.
2. To offer professional training to health care professionals involved in the health information and education of hard-to-reach patients. This will be done through in-service workshops in the three participating units.
3. To gather and disseminate information and findings concerning health literacy. We identified key Canadian players and institutions involved in health literacy in Section 3 of the Health Literacy Background Document. Findings, evaluation results and lessons learned will be disseminated to these potential collaborators and other stakeholders in the larger health/literacy community. This will be done through oral, written and on-line reports, briefings, newsletters, working papers and journal articles. We will also inform and exchange with the health literacy community in the United States and internationally.
4. To evaluate the effectiveness of the strategies used to improve the health information given to and health education of hard-to-reach patients and their families. This ongoing evaluation will serve to improve the education strategies used in the three pilot Health Education Centres.

3.3 Recommendations

General Recommendations

1. *One pilot Health Education Centre should be set up in each participating unit.*

Rationale

Informants told us that Health Education Centres must be close to where patients come for their treatment or medical appointment and easily accessible. Patients and families said that they would probably come to the Centre while waiting for their treatment, their blood test, to meet the nurse or the doctor, etc. Because the treatment schedules of patients vary, they should be able to access the Health Education Centre at any time during the workday. Most patients would not walk across the hospital to visit an Education Centre.

Following the advice of both health care professionals and patients, one specific room in each unit should be designated as the hub for a number of different activities and programs. This is where users would find human resources, written resources, visual material and space for one to one meetings and small classes. Video presentations and patient discussion groups could take place elsewhere.

During the Needs Assessment, health care workers identified potential sites for pilots:

- In Oncology Hematology, the family room is the most likely at this time.
- In Dialysis, the conference room is a possibility, although it is used for research and meetings.
- In the Pre-Op Centre, there is space available on the 10th floor.

Human resources

2. *A health care professional should be responsible for coordinating the Centres on a part-time basis.*

Rationale

Based on the advice of interviewed patients and health care professionals and the need for continuity in the units, it is better to have a health care professional take on the role of coordinator rather than have an outside consultant who comes “in and out.” This would help build the knowledge and capacity within the unit. The coordinators could also serve as resource people for small classes, presentations, one-to-one meetings, etc.

3. *Volunteers, including former patients, should be available to staff the Centres and be involved in programming, under the supervision of the health care coordinator.*
4. *Patients and families who use the information services of the Centre, and participate in the programs and activities, should be involved in evaluating them.*
5. *Education Committee, composed of a patient representative from the unit, a family representative from the unit, the health care professional in the position of co-ordinator, a representative from the Health Literacy Steering Committee, and possibly a volunteer and a support staff member, should oversee each pilot Centre.*
6. *Groups, composed of patients, families and health care professionals in each unit, should develop their own guiding principles and hypotheses, using this report as a starting point. The Education Committees could facilitate these group processes.*

7. *The **Health Literacy Steering Committee**, as the driving force behind the entire project, should assume a co-ordinating and research management role for all three pilot Centres.*

Rationale

Patients told us that they want to be involved in setting up and running the Centres. We know that families play a key role in the education process of hard-to-reach patients. Patients and families should identify their information and education needs and give advice on how to improve what is offered. Patients could also be trained to animate patient group discussions, develop health material and share their experience with others inside and outside the hospital. Many indicated an interest in using participatory approaches.

The composition of the Education Committees will help ensure that the interests of all the parties are met. The co-ordination by the Health Literacy Steering Committee (whose composition should be expanded to include one representative from each of the three units) will keep all the pilot projects on track in meeting the overall objectives.

While the term “Health Education Centres” is the one being used for the purpose of planning Phase 2, groups composed of patients, families and health care professionals in each unit could find a less generic name for the pilot centre, one that reflects more specifically their own perception of their Centre.

Information services, activities and programs

8. *The Centres should develop **multi-faceted approaches** to patient information and activities, and offer different kinds of health information to meet the different needs of patients and caregivers.*

Rationale

The Needs Assessment told us what patients and caregivers want to know. To develop the specific content of the information, this input should be used to prepare new information handouts and teaching tools for hard-to-reach patients. This information, much of it is specific to each unit, is included in Appendices 5 and 6. The Needs Assessment also told us how patients and caregivers like to learn. The pilot Health Education Centres should use and offer different learning tools including better designed written materials in plain language; printed resources such as newsletters, journals, publications from patient support groups, etc.; visual material: posters, pictograms, etc.; health videos for patients to borrow and watch at the Centre; and games, Q&A, booklets with cartoons, etc. The activities in the Centres should reflect these findings, and include one-to-one meetings with health care workers; small classes and workshops on specific topics; oral presentations by health care workers; and patient discussion groups and other participatory group processes.

9. *Computers and computer-based education should not be a preferred option in the short term.*

Rationale

Considering the lack of interest on the part of interviewed patients and the large financial investments needed for a computer-based patient education program, this should not be a priority in the short term.

10. Financial resources should be allocated to research, borrow, adapt, reproduce or produce, if necessary, written material and videos offering basic health information in Italian, Greek, Spanish, Cree, and possibly other languages to be identified.

Rationale

During the Needs Assessment, patients who face language barriers repeatedly expressed the incredible challenge of learning about their health and understanding their health care. Language represents a formidable barrier with written materials, oral communication, videos, patient group discussions and any form of communication not based on pictograms. Many patients emphasized their need for a family member or an interpreter to be present. They wished that more health care workers could speak their language. They also requested translated written materials, translated videos and visual materials with simple words. The most common “other languages” among this group of patients were Italian, Greek, Spanish and Cree (See Appendix 5 for languages of interviewed patients). Health care professionals also said that basic health information should be available in other languages. The satellite dialysis units in Northern Québec could use the health material produced in Cree. The increased use of visual material and pictograms should also help inform hard-to-reach patients who face language barriers.

11. A professional development training program for health care workers should be designed.

Rationale

Findings from the Needs Assessment regarding what health care professionals know about health literacy confirm the need for training. These professionals have difficulty identifying hard-to-reach patients and determining their specific information and education needs. Many health care professionals worry about patient comprehension, and they agreed that the Health Education Centres should co-ordinate training to focus on the ways health care professionals interact with hard-to-reach patients. Topics covered could include how to identify hard-to-reach patients; how to assess the education needs of hard-to-reach patients; how to effectively communicate with and teach hard-to-reach patients (including plain language oral communication); and how to validate the teaching.

12. Participatory group activities should be planned with patients and caregivers.

Rationale

The Needs Assessment revealed that patients and family members are not familiar with ways of learning other than written information, oral communication and videos. It is important to familiarize them with other ways of learning, for example, patient group discussions could be introduced progressively. These group processes should be encouraged in general to develop group cohesiveness and empowerment among patients and caregivers, particularly in the dialysis unit. For example, health material could be developed by patients and families. While the literature mentions the use of drama as a participatory approach to health literacy, the Needs Assessment revealed that the use of drama with patients from the three participating units would probably not work well.

Creating the right environment and promoting the Centres

13. The Centres should offer a friendly, welcoming atmosphere free of stress and anxiety.

14. The first visit to a Centre should become part of the intake and orientation process followed by new patients.

Rationale

The Needs Assessment showed that, for the majority of interviewed patients, the hospital is the single most preferred location for learning. The Centres' space should be attractive and not look like a hospital room. It should have an attractive name. Patients who like to learn at home indicated that it was because they felt relaxed, at ease and unrushed. Informants said that anxiety interferes with learning. For example, according to Oncology Hematology nurses, a large part of what is taught to their patients is lost because patients are very anxious on the first day of treatment. Patients at the Centres should be able to take their time and not be rushed. The Needs Assessment revealed that time is not an issue for most of these patients; among those interviewed, only one works full-time and one part-time. While Dialysis patients are often in a hurry to return home after the treatment, the Needs Assessment revealed that they could have time before the treatment to visit the Centre. Interviewed patients mentioned the importance of respect and the desire to have all their questions answered. Patients and families should feel relaxed and respected and comfortable enough to ask all their questions. Staff and volunteers should be trained to accept different needs and diverse ways of learning.

15. That special steps be taken to accommodate the group of patients who may be hesitant to use such Centres.

Rationale

Health care professionals identified the particular challenge of attracting hard-to-reach patients to the Centres. Promoting the Centres among patients and families should be a priority. Promotion strategies such as offering light snacks and free handouts and showing "fun" videos could be used to attract users. One interviewed patient recommended that the Centres should be very good at public relations, informing patients and families in a clear and simple way about the Centre's agenda each day /each week/each month, in order that they can determine if they need or want to participate. Informants told us that patients and families should be specifically invited to use the information services (read written information, borrow videos, learn from visual materials, etc.) and participate in the activities and programs (small classes, one-to-one meetings, presentations, workshops, discussion groups, evaluation sessions, etc.).

Special efforts should be made to attract hard-to-reach patients to the Centres. The Needs Assessment confirmed the importance of the human relationship and the building of trust between patients and health care professionals. A good strategy could be to have health care workers, with whom patients have a strong human relationship and a high level of trust, convince them to make use of the Centres. The Needs Assessment also revealed the central role of caregivers in the education process of hard-to-reach patients, and they could also be used to promote the Centres. Additional outreach efforts should be targeted to hard-to-reach patients who appear not to want to learn about their illness or hesitate about going to the Centres.

16. A system should be developed so those patients who go to the Centres do not lose their “place in line” (if there is one) for their treatment or appointment.

Rationale

The patient’s priority is not to miss an appointment or a treatment. Patients should be assured that going to the Centre will not make them late or miss their turn. There should be a way for medical staff to easily contact patients in the Centre when it is time for the patient’s treatment. This gesture would demonstrate the value that staff place on the Centres and show sensitivity for the patients’ reality.

3.4 Areas for Further Investigation

The analysis in this report has focused on the objectives of identifying the communication needs of hard-to-reach patients and making recommendations for pilot health education centres to test some of the hypotheses developed from the study. The data, however, provides a rich deposit for further investigation, as pointed out in feedback from the evaluator, Dr. William Ninacs. He has identified three potential areas for further investigation that could be fruitful. There are likely several more.

1. On the question of who are the hard-to-reach patients, a re-analysis of the data in the appendices could lead to a set of descriptors of the characteristics of this diverse group.
2. The data could be looked at in terms of the empowerment process using an analytical framework on empowerment. This analysis could investigate the different perspectives on empowerment from the point of view of patients, caregivers, and health care workers.

The group of hard-core “hard-to-reach” patients could warrant further exploration.

APPENDICES

Appendix 1. Steering Committee members

The members of the Steering Committee on Health Literacy of the Montreal General Hospital are:

- ◆ Donna Ahern, Patients' Advocate, Montreal General Hospital (MUHC)
- ◆ Michelle Bourgeois, Physiotherapist, Montreal General Hospital (MUHC)
- ◆ Louise Duguay, Nurse Educator, Montreal General Hospital (MUHC)
- ◆ Lynn Kiraly-Batist, Librarian, Nurses' Library, Montreal General Hospital (MUHC)
- ◆ Denise Malo, Associate Director, Academic Practice and Professional Development, Montreal General Hospital (MUHC)
- ◆ Nadine Osborne, Project Officer, Health Canada
- ◆ Lisa Rosati-White, Patients' Advocate, Montreal General Hospital (MUHC)
- ◆ Dr. Linda Shohet, Director, The Centre for Literacy of Québec

Principal researcher: Odette Langlais, consultant in education

Co-researcher: Charles Draper, consultant

Associate researcher: Claire Elliott, Librarian, The Centre for Literacy of Québec

External evaluator: Dr. William Ninacs, Chairperson, *Coopérative de consultation en développement La Clé*

Proof reader: Sally Selvadurai, The Centre for Literacy of Québec

Editor: Dr. Linda Shohet, The Centre for Literacy of Québec

Appendix 2. Needs Assessment research plan

The original research plan was developed in February 2000 and approved by the Steering Committee.

General design

For the Needs Assessment, we will use two instruments for data collection:

1. Individual interviews using a bilingual questionnaire. The questionnaire will be adapted for patients, caregivers, support staff, and health care professionals
2. Focus groups

The Needs Assessment has been designed to answer two key questions:

- What are the health education needs of hard-to-reach patients⁹ and how can we meet those needs?
- What are the needs of health care professionals in terms of the health education of their patients and how can we meet those needs?

To identify the needs of hard-to-reach patients, we will consult four groups of informants: patients, their families and caregivers, support staff, and health care professionals from the three participating units: Dialysis, Pre-operative Centre, and Oncology Hematology. We will also identify the needs of health care professionals from two CLSC's in the area (CLSC Guy Metro, and CLSC Côte-des-Neiges). The following chart indicates the number of **planned** individual meetings and focus groups. Final numbers can be found in Appendices 6, 7, and 8.

| Data Collection Instrument | Patients | Caregivers | Support Staff | Health Care Professionals |
|---|---|---|---|--|
| Individual Interviews with Questionnaire | Hard-to-reach patients from three units Total: 30 | Caregivers from three units Total: 10 | Support staff from three units Total: 5 | Health care professionals from three units and other health care centres Total: 15 |
| Focus Groups | One per unit Total: 3 | Total: 2 | Total: 1 | One per unit Total: 3 |
| One or two mixed focus groups | | | | |

⁹ **Hard-to-reach patients** has been defined to include low-literate patients, patients with language or cultural barriers and patients with learning difficulties due to cognitive or physical disabilities

Individual interviews

The procedure will begin by obtaining informed consent from participants. Each individual will read (or the researcher will read) the informed consent form which meets the requirements of the Montreal General Hospital Research Ethics Committee. A copy of the informed consent form is included at the end of this plan (included in Appendix 3 in this Report). The two researchers will fill out a questionnaire with each individual in English or in French. This will take approximately 30 minutes. Individual interviews will take place in each of the three units and in the CLSCs for some health care professionals. Researchers will be careful not to disturb the routine of the unit or the work of the nurses and other professionals.

Patients

We will attempt to interview one-third English, one-third French and one-third patients from ethno-cultural communities, as well as attempt to balance gender, age group and socio-economic background. Nursing staff from each unit will help us identify hard-to-reach patients. We suggest the use of indicators such as:

- General difficulties in reading and understanding information (e.g., patients who repeat the same questions; who return repeatedly with the same issues; or those who have a blank look during information sessions);
- Socio-economic background;
- Education level, if such information is available;
- Learning difficulties due to cognitive or physical disabilities;
- Cultural barriers;
- Language barriers (i.e., lack of fluency in either or both English and French).

Once a potential candidate is identified, the nursing staff will approach the individual and ask if he or she would like to participate in an individual meeting. This is required by the Research Ethics Committee. If the answer is positive, the researcher will approach the patient, read the Informed Consent Form, get it signed, and proceed with the individual meeting.

Caregivers

When we interview patients, we will ask them if we can meet with their caregiver. We will explain that their point of view is important for this study. We will add that they can say no, and even if they agree, their caregiver can say no. If the patient agrees, we will approach the caregiver and ask them if they wish to participate.

Support staff

We will ask these support staff from each participating unit (i.e., Dialysis technicians and patient attendants).

Health care professionals

We will ask the nursing staff and other health care professionals from each participating unit and from the CLSC's.

Focus groups

For each unit, we plan to hold one focus group with patients and one with health care professionals. We also plan to hold two focus groups for caregivers and one for support staff. If possible, we will attempt to hold one or two mixed focus groups with patients, caregivers and health care professionals. It may be difficult from a logistics point of view to mix individuals from the three units since they each have a different schedule.

The objective of the focus groups is to initiate a group dynamic, to encourage collective exchanges and to facilitate group discussion. This will enable us to deepen and add a collective perspective to the data collected through individual meetings. We may ask the group what they think of opposing opinions or controversial issues that arise in the individual meetings and launch “trial balloons” regarding the Health Literacy Centre¹⁰.

Methodology

We will use the methodology of *Concept Mapping* in the group meetings. This methodology facilitates the participation of all those present. It eliminates the risk of having one or two individuals dominate the conversation. The animator plays a facilitating role. Key questions are posted on the wall as well as answers from participants. Everyone can see the evolution of the discussion and the results of working together. The results from the focus groups then comprise a synthesis and analysis of the contributions of each participant.

Sampling

Patients

For focus groups, we will use a cross-section of patients from the three units, assuming that a fair percentage of hard-to-reach patients will be represented. We anticipate that the health literacy difficulties we uncover would apply to low-literate as well as more literate patients. It will be a challenge to set up focus groups with patients who are receiving long and tiring treatments (dialysis and chemotherapy). We could possibly plan a small luncheon.

Health care professionals

We will ask the staff from the three units, a mix of those who filled out the questionnaire and those who did not.

Caregivers and support staff

We will ask those who responded to the questionnaires, and if additional input is needed, others who did not.

¹⁰ Until the research process was under way, we were calling the proposed centres, Health Literacy Centres.

Appendix 3: Informed Consent Form

The Informed Consent Form, used to recruit individual interview and focus group participants, was approved by the Research and Ethics Committee of the Montreal General Hospital, MUHC.

Informed Consent Form

Study Title: **Health Education Project: Needs Assessment**

Investigators:

- Linda Shohet, Principal investigator, Director, The Centre for Literacy of Québec
- Denise Malo, Co-investigator, Montreal General Hospital
- Odette Langlais, Principal researcher

Health Canada has provided financial support for this project.

The Study:

We are doing a study to improve health education for patients at the Montreal General Hospital. We would like to invite you to participate in this study. Your ideas about the kind of health information that is given to patients will be very helpful to us. You can help us understand how we can improve health education for patients.

This is a project of the Montreal General Hospital and The Centre for Literacy of Québec. To improve patient education at the hospital, we want to set up a Health Education Centre. This Centre will inform patients and their families about their health and healthcare. It will:

1. Give information and all kinds of classes and teaching for patients and their families;
2. Help health care workers communicate better with patients;
3. Collect and give out information and findings about health education.

The first phase of the project is the Needs Assessment. Three units in the hospital are participating: Dialysis, Pre-op Centre and Oncology Hematology. We want to ask patients, caregivers, health care workers and support staff about the health education needs of patients. We also want to ask health care workers what are their needs as educators.

Your Participation:

You are completely free to participate or not. If you refuse to participate or decide to leave the study, this will not affect in any way your health care or your benefits. We invite you to participate in:

1. An individual interview. You will spend about 30 minutes with the researcher (only once). They will ask you about what you need in terms of health information and health education. They will write down the answers.

AND / OR

2. A small-group discussion of about one hour. You will discuss patient health education with others.

Confidentiality

All your answers to the questions and what you say during the discussion is strictly confidential. We will not write down your name on the questionnaire. We will keep records in a safe location. The researcher will ask you questions and collect information. He or she will not be able to help you with your current health needs. If information is given to the researcher that should be communicated to the health care worker (important information for the patient's health), then verbal consent will be obtained from the patient or the caregiver to communicate this to the health worker. The Research Ethic Committee of the Montreal General Hospital may look at research records from this study. This is to verify that the research is done in agreement with Montreal General Hospital and the Montreal General Hospital Research regulations for research involving humans.

Risks and Potential Benefits

There are no foreseen risks for you to participate in this study. There are no immediate benefits either. However, we hope to improve the way information is provided to patients at the hospital in the medium to long term.

Compensation

There is no compensation offered for your participation in this study.

Contact Persons

If you have questions about your rights as a participant in this study, please contact Mr. Glen Fash, the Representative of the Patient's Committee at (514) 937-6011, ext.2409. If you have any questions regarding your participation in this research study, you should contact Linda Shohet, principal investigator, Director, Centre for Literacy of Québec at (514) 931-8731, ext.1411; Denise Malo, co-investigator, Montreal General Hospital at (514) 937-6011, ext.4183; or Odette Langlais, principal researcher, at (819) 827-9124.

A Steering Committee looks after this project. It is composed of hospital staff, patient representatives, the Director of The Centre for Literacy and a person from Health Canada. The Steering Committee has hired two researchers to do the Needs Assessment: Odette Langlais and Charles Draper.

I understand the information in this form.
 I was able to ask questions and I am satisfied with the answers.
 I agree to participate in the Needs Assessment.
 I have been given a signed copy of the consent form.
 I do not give up any of my legal rights by signing this form.

 Signed by Participant

 Print name

 Signed by Researcher

 Print name

 Signed by Witness/Translator

 Print name

Date: _____

Appendix 4. Ethical concerns and accommodations

The Research and Ethics Committee of the Montreal General Hospital requested an external review of our proposal. The review and other issues, such as confidentiality and the specific wording of the Informed Consent Form, were discussed by the Research and Ethics Committee during one of their monthly meetings. The Needs Assessment proposal was reviewed and approved by the Committee on March 14th 2001. We have outlined below some of the key concerns raised by the external reviewer, William Ninacs, and the Research and Ethics Committee regarding the data collection. We explain briefly how the researchers accommodated the concerns and what actually happened during the collection process.

CONCERN: How research will be presented to patients when approached by staff

We asked nurses to phrase their request as follows: “Would you like to participate in a study to improve patient education? You will meet a researcher who will talk to you and take notes for about 30 minutes.” This was acceptable.

CONCERN: Patients will feel negatively labelled

This was not a problem because of the way the research was presented by the nurses on the floor. Patients did not know that they were being interviewed because they were considered hard-to-reach. They were generally very happy to participate and to talk to us. Many needed to tell their story. Some interviews lasted up to an hour or even 90 minutes! Even though we did not ask them questions about their illness, some wanted to talk about it and to debrief what they were going through. Four patients, all from Dialysis, did not agree to the interview, three of them because they were tired or did not feel well. For the focus groups, we tried to make the atmosphere as informal and friendly as possible and did our best to accommodate the needs of those with physical disabilities.

CONCERN: Patients will not understand the questions asked

We tried to ask questions clearly, simply and to use plain language. Overall, the large majority of patients understood the questions and answered what they thought. In some cases, the language barriers or the cognitive difficulties did prevent patients from understanding questions, but this was rare. Some family members were not very good at translating the questions and the answers. One patient had such serious cognitive and speech difficulties that the questionnaire was only half-filled. Sometimes we faced interruptions but could pursue the interview later, e.g. a patient would feel ill (ex. coughing, feeling nauseous) or be overcome by sadness in the middle of the interview.

CONCERN: Patients will think researcher is a health care provider and confide health information

This was not a problem. We explained clearly at the beginning that we were not nurses, and that we would ask patients for their verbal consent to share information with their health care provider if they confided important health-related information. This was also included in the Informed Consent.

CONCERN: Patients will only answer questions, but will not be “actively engaged”

This was not the case. They did answer questions, but we also asked them to tell us what we could do better. We encouraged them to find solutions and to offer suggestions on how to

improve patient education, how to improve written information, what to offer in the Health Education Centre, etc.. They were actively involved in finding solutions during the focus groups. Patients did have a voice, an opportunity to talk and express their needs.

CONCERN: Methodology must be culturally-sensitive

Everything was done in English or French as needed. We were careful to proceed slowly and simply with patients who spoke another first language (with or without an interpreter). Though not part of the research plan, both researchers could do interviews in Spanish, which was appreciated. For other languages and cultures, we showed a lot of interest in the countries of origin and the different cultures. The interview with the Cree interpreter gave us insight into the language and cultural barriers faced by Cree patients.

CONCERN: Patients will face difficult power relationships in mixed focus groups

We decided not to hold mixed focus groups for this reason.

CONCERN: The extra work placed on staff will be a burden because of a shortage of human resources

In the units, we were discreet while getting the work done. A few times, we left when we were told that “this was not a good day.” It was a challenge not to disturb the nurses since we needed their help in identifying hard-to-reach patients and asking for their participation. When we filled out questionnaires with nurses, we were careful to come at the most appropriate time of the day. The fact that all Pre-op nurses answered the individual questionnaires and that we had such a high level of participation of nurses in the Dialysis and Oncology Hematology focus groups reflects a high-level of collaboration. Overall, we established very positive relationships with the head nurses. The data collection process raised a high level of interest in the issue of hard-to-reach patients. It was not a problem to meet the staff at the CLSCs.

Appendix 5. Questionnaires used in interviews

PATIENT QUESTIONNAIRE

General Information – Information générale:

Gender - *genre*

Age

Work / job - *travail / emploi*

First language - *première langue*

Part 1. What you are learning now about your health

Première partie. Ce qui vous est offert pour apprendre sur votre santé

1.1 What kind of information do you need to know to take good care of yourself? (*ask open-ended question and then offer possible answers if patient has problems answering.

Indicate answers using the multiple answers and add others if necessary). - *Quel genre d'information avez-vous de besoin pour pouvoir bien prendre soin de votre santé? (*poser la question et si le patient a de la difficulté à répondre, donnez-lui des réponses possibles. Indiquer les réponses en cochant et ajouter les autres réponses si nécessaire).*

- Medical information about the illness - *information médicale sur la maladie*
- Information about daily living: diet, exercise, activity level, etc. - *information sur la vie quotidienne: la diète, les exercices, le niveau d'activité physique, etc.*
- Teaching about how to take medication, about tests (ex. blood, x-ray, radiotherapy), etc. - *enseignement sur comment prendre les médicaments, les tests (de sang, rayons x, radiothérapie), etc.*
- Information about how you feel, how you cope, how the illness has changed your life - *information sur comment on se sent, comment "dealer" avec la maladie, comment la maladie a changé sa vie*
- Information about how the illness has changed your family life - *information sur comment la maladie a changé la vie de famille*
- Information about health places in the community - *information sur les services de santé en-dehors de l'hôpital*
- Information about how to get around the hospital - *information sur comment se retrouver dans l'hôpital*
- Help to fill out forms - *de l'aide pour remplir les formulaires*

1.2 Let's have a look at - *Regardons*:

- a) Written information such as pamphlets, forms, booklets, handouts, etc. - *Information écrite: dépliants, livrets, feuillet d'information, etc.*

Show example of commonly used handouts from the unit and ask questions: -

Montrer un exemple d'un livret souvent utilisé par l'unité et poser les questions:

- Tell me about the information in this booklet. - *Parlez-moi de l'information dans ce livret.*
- Is the information useful to you? Can you use it at home? - *Est-ce que cette information est utile pour vous? Pouvez-vous vous en servir à la maison?*
- What do you like / not like about it? - *Qu'est-ce que vous aimez, n'aimez-pas dans ce livret?*
- What is easiest to understand? - *Qu'est-ce qui est plus facile à comprendre?*
- How can we make it easier for you to use? - *Comment peut-on rendre ce livret plus utile pour vous?*

- b) What about when your doctor, the nurse or another health care worker talks to you? - *Quand votre médecin, l'infirmière ou un autre professionnel de la santé vous explique quelque chose:*

- What do you like/not like when they talk to you? How could it be better? - *Qu'est-ce que vous aimez / n'aimez-pas lorsqu'il ou elle vous parle? Comment est-ce que cela pourrait être mieux pour vous?*
- Do you find it easy to use what they tell you? - *Est-ce que c'est facile de mettre en pratique ce qu'ils vous disent?*
- What advice would you give them? - *Quels conseils pourriez-vous leur donner?*

- c) What about: - *Qu'est que vous pensez de:*

- Videos about health. - *Les cassettes video sur la santé.*
- Group discussions with other patients. - *Les groupes de discussion avec d'autres patients.*
- Information sessions or workshops in a health clinic or a CLSC. - *Les sessions d'information ou les ateliers dans les CLSC.*
 - Have you used any of them? - *Est-ce que vous les utilisez?*
 - What did you think of them? - *Qu'en pensez-vous?*
 - What did you like/dislike about them? - *Qu'est ce que vous aimez / n'aimez pas?*
 - How could they be better? - *Comment est-ce qu'ils pourraient être plus utiles?*

1.3 Are the signs clear enough to get around the hospital? *Est-ce que les indications pour se retrouver dans l'hôpital sont assez claires?*

1.4 Are Hospital forms easy to fill out? *Est-ce que les formulaires de l'hôpital sont faciles à remplir?*

Part 2. How you learn best

Partie 2. Comment vous apprenez le mieux

2.1 To learn about your health - *Pour apprendre au sujet de votre santé*

- Do you like to be alone with a teacher? - *Aimez-vous être seul(e) avec un enseignant?*
yes - *oui* ___ no - *non* ___
- Do you like to be learning in a group with other patients? *Aimez-vous apprendre dans un groupe avec d'autres patients?*
yes - *oui* ___ no - *non* ___
- Do you like to read information? - *Aimez-vous lire de l'information?*
yes - *oui* ___ no - *non* ___
- Do you like to watch a video? - *Aimez-vous regarder un video?*
yes - *oui* ___ no - *non* ___
- Do you like to have someone explain it you verbally? - *Aimez-vous que quelqu'un vous explique quelque chose?*
yes - *oui* ___ no - *non* ___

2.2 If you have a question, do you prefer to: - *Si vous avez une question, préférez-vous*

- Ask the doctor - *la demander au médecin*
- Ask a nurse - *ou la demander à l'infirmière*
- Ask someone else such as patient, family, friend (specify who) - *la demander à un autre patient, un membre de votre famille, ou ami (indiquer qui)*

2.3 To learn about your health (give example), would you rather be - *Pour apprendre sur votre santé (donner un exemple), préférez-vous être*

- In the hospital or - *à l'hôpital*
- In a CLSC or - *dans un CLSC ou*
- In a community centre or - *dans un centre communautaire ou*
- Home or - *à la maison ou*
- Elsewhere (specify where) - *ailleurs (indiquer où)*

2.4 If you have a skill to learn (mention a skill needed for patients in that unit), do you prefer to - *Si vous devez apprendre une procédure (mentionner une procédure que les patients doivent apprendre dans cette unité), préférez-vous*

- Practice alone or - *pratiquer seul ou*
- In front of a health care worker? - *devant un travailleur de la santé?*

2.5 What kind of place makes it easier for you to learn? Dans quel genre d'endroit êtes-vous bien pour apprendre?

2.6 What makes you comfortable when you are learning in a group? Qu'est-ce qui vous rend confortable lorsque vous apprenez dans un groupe?

2.7 What makes a good teacher? Qu'est-ce qui fait un bon professeur?

2.8 Do you use a computer? Do you like to use a computer? Does it help you learn?

Utilisez-vous un ordinateur? Aimez-vous utiliser un ordinateur? Est-ce que cela vous aide à apprendre?

Part 3. The planned Health Education Centre

Partie 3. Le Centre d'éducation à la santé

After we identify the needs of patients, we want to have a Centre to help you learn. There would be a place in the hospital called the Health Education Centre. We would like you to dream, to imagine. What should it be like? - *Lorsqu'on en saura plus sur les besoins des patients, on veut mettre sur pied un centre pour les patients et leurs familles. Il y aura un endroit dans l'hôpital appelé Centre d'éducation à la santé. On veut savoir ce que vous aimeriez avoir dans ce centre. On vous invite à imaginer, à rêver.*

Sub-questions to help along: - *Sous-questions:*

- What do you think patients could do? - *Qu'est-ce que vous pensez que les patients pourraient faire dans ce centre?*
- Would it be in one place in the hospital or in many different places? - *Est-ce que le Centre serait à un endroit ou dans plusieurs endroits différents?*
- Who would take care of it? (patients or health care workers or volunteers or a mix) - *Qui pourrait gérer le Centre? Les patients, les bénévoles, les professionnels de la santé?*
- How would families use it? - *Comment les familles pourraient-elles l'utiliser?*
- Do you see a place for videos, computer programs, drama, etc.? - *Est-ce que vous croyez que l'on devrait avoir des cassettes videos, des programmes d'ordinateurs, des pièces de théâtre?*
- Would it involve training doctors, nurses, etc. to communicate better with patients? - *Est-ce que l'on devrait former les médecins et les infirmières à mieux communiquer avec les patients?*

Final question - *question finale:*

Do you have something else to tell us about health information and education for patients?
Avez-vous autre chose à nous dire sur l'information sur la santé donnée aux patients et l'enseignement aux patients?

CAREGIVER QUESTIONNAIRE

General information – Information générale:

Gender - *genre*

Age

Work / job - *travail / emploi*

First language - *première langue*

Role of caregiver - *rôle du membre de la famille du patient*

Part 1. What your family member is learning now about his/her health

Première partie. Ce que le membre de votre famille apprend sur sa santé

1.1 What kind of information do you and your family members need to know to take good care of his/her health? (*ask open-ended question and then offer possible answers if patient has problems answering. Indicate answers using the multiple answers and add others if necessary). - *Quel genre d'information avez-vous de besoin, vous et le membre de votre famille, pour pouvoir bien prendre soin de son santé? (*poser la question et si le patient a de la difficulté à répondre, donnez-lui des réponses possibles. Indiquer les réponses en cochant et ajouter les autres réponses si nécessaire).*

- Medical information about the illness - *information médicale sur la maladie*
- Information about daily living: diet, exercise, activity level, etc. - *information sur la vie quotidienne: la diète, les exercices, le niveau d'activité physique, etc.*
- Teaching about how to take medication, about tests (ex. blood, x-ray, radiotherapy), etc. - *enseignement sur comment prendre les médicaments, les tests (de sang, rayons x, radiothérapie), etc.*
- Information about how you feel, how you cope, how the illness has changed your life - *information sur comment on se sent, comment "dealer" avec la maladie, comment la maladie a changé sa vie*
- Information about how the illness has changed your family life - *information sur comment la maladie a changé la vie de famille*
- Information about health places in the community - *information sur les services de santé en-dehors de l'hôpital*
- Information about how to get around the hospital - *information sur comment se retrouver dans l'hôpital*
- Help to fill out forms - *de l'aide pour remplir les formulaires*

1.2 Let's have a look at - *Regardons*:

- a) Written information such as pamphlets, forms, booklets, handouts, etc. - *Information écrite: dépliants, livrets, feuillet d'information, etc.*

Show example of commonly used handouts from the unit and ask questions: -
Montrer un exemple d'un livret souvent utilisé par l'unité et poser les questions:

- Tell me about the information in this booklet. - *Parlez-moi de l'information dans ce livret.*
 - Is the information useful to you? Can you use it at home? - *Est-ce que cette information est utile pour vous? Pouvez-vous vous en servir à la maison?*
 - What do you like / not like about it? - *Qu'est-ce que vous aimez, n'aimez-pas dans ce livret?*
 - What is easiest to understand? - *Qu'est-ce qui est plus facile à comprendre?*
 - How can we make it easier for you to use? - *Comment peut-on rendre ce livret plus utile pour vous?*
- b) What about when your doctor, the nurse or another health care worker talks to you? -
Quand votre médecin, l'infirmière ou un autre professionnel de la santé vous explique quelque chose:
- What do you like/not like when they talk to you? How could it be better? - *Qu'est-ce que vous aimez / n'aimez-pas lorsqu'il ou elle vous parle? Comment est-ce que cela pourrait être mieux pour vous?*
 - Do you find it easy to use what they tell you? - *Est-ce que c'est facile de mettre en pratique ce qu'ils vous disent?*
 - What advice would you give them? - *Quels conseils pourriez-vous leur donner?*
- c) What about: - *Qu'est que vous pensez de:*
- Videos about health. - *Les cassettes video sur la santé.*
 - Group discussions with other patients. - *Les groupes de discussion avec d'autres patients.*
 - Information sessions or workshops in a health clinic or a CLSC. - *Les sessions d'information ou les ateliers dans les CLSC.*
 - Have you used any of them? - *Est-ce que vous les utilisez?*
 - What did you think of them? - *Qu'en pensez-vous?*
 - What did you like/dislike about them? - *Qu'est ce que vous aimez / n'aimez pas?*
 - How could they be better? - *Comment est-ce qu'ils pourraient être plus utiles?*

1.3 Are the signs clear enough to get around the hospital? *Est-ce que les indications pour se retrouver dans l'hôpital sont assez claires?*

1.4 Are Hospital forms easy to fill out? *Est-ce que les formulaires de l'hôpital sont faciles à remplir?*

Part 2. The planned Health Education Centre *Partie 2. Le Centre d'éducation à la Santé*

After we identify the needs of patients, we want to have a Centre to help you and your family learn. There would be a place in the hospital called the Health Education Centre. We would like you to dream, to imagine. What should it be like? - *Lorsqu'on en saura plus sur les besoins des patients, on veut mettre sur pied un centre pour les patients et leurs familles. Il y aura un endroit dans l'hôpital appelé Centre d'éducation à la santé. On veut savoir ce que vous aimeriez avoir dans ce centre. On vous invite à imaginer, à rêver.*

Sub-questions to help along: - Sous-questions:

- What do you think patients could do? - *Qu'est-ce que vous pensez que les patients pourraient faire dans ce centre?*
- Would it be in one place in the hospital or in many different places? - *Est-ce que le Centre serait à un endroit ou dans plusieurs endroits différents?*
- Who would take care of it? (patients or health care workers or volunteers or a mix) - *Qui pourrait gérer le Centre? Les patients, les bénévoles, les professionnels de la santé?*
- How would families use it? - *Comment les familles pourraient-elles l'utiliser?*
- Do you see a place for videos, computer programs, drama, etc.? - *Est-ce que vous croyez que l'on devrait avoir des cassettes videos, des programmes d'ordinateurs, des pièces de théâtre?*
- Would it involve training doctors, nurses, etc. to communicate better with patients? - *Est-ce que l'on devrait former les médecins et les infirmières à mieux communiquer avec les patients?*

Final question - question finale:

Do you have something else to tell us about health information and education for patients?
Avez-vous autre chose à nous dire sur l'information sur la santé donnée aux patients et l'enseignement aux patients?

SUPPORT STAFF QUESTIONNAIRE

General information - Information générale:

Gender - *genre*

Age

First language - *première langue*

1. Do patients come to you with questions? If yes, what questions do they ask you? How do you handle it? Why do you think they ask you?
Est-ce que les patients vous posent des questions parfois? Si oui, quelles questions posent-ils? Comment répondez-vous? Pourquoi pensez-vous qu'ils vous posent ces questions?
2. How do you think we could improve health information and education for patients?
À votre avis, comment pourrait-on améliorer l'information sur la santé qui est donnée aux patients et aussi ce qui est enseigné aux patients?
3. We would like to put together a new Health Education Centre at the hospital for patients and their families. What could it be like? What do you see as part of it? What do you think patients could do?
Nous voulons mettre sur pied un nouveau Centre d'éducation sur la santé à l'hôpital pour les patients et leurs familles. Comment voyez-vous un tel centre? Qu'est-ce qu'on pourrait trouver dans un centre d'éducation à la santé? Qu'est-ce que pourraient faire les patients?
4. Do you have something else to tell us about health information and education for patients?
Avez-vous autre chose à me dire au sujet de l'éducation des patients et de l'information donnée aux patients?

HEALTH CARE PROFESSIONAL QUESTIONNAIRE

General information – Information générale:

Gender - *genre*

Age

Profession - *profession*

Part 1. What you know about health literacy and low-literate patients

Première partie. Ce que vous savez sur les questions d’alphabétisme et de santé

- 1.1 What does low literacy mean to you? - *Est-ce que le terme “faible niveau d’alphabétisme” vous dit quelque chose?*
- 1.2 What does low health literacy mean to you? - *Que veut dire un “faible niveau d’alphabétisme” dans un contexte de santé?*
- 1.3 How would you describe low-literate patients? What do these patients look like, sound like, act like? - *Comment pourrait-on décrire les patients faibles lecteurs? De quoi ont-ils l’air, comment se comportent-ils?*
- 1.4 How do you handle it when you are teaching a low-literate patient? - *Que changez-vous lorsque vous enseignez à un patient faible lecteur?*

Part 2. The health education needs of hard-to-reach patients

Partie 2. Les besoins des patients « difficiles à rejoindre »

- 2.1 What do you think are the health education needs of hard-to-reach patients in this unit or this CLSC? - *À votre avis, quels sont les besoins en terme d’information et d’éducation à la santé des patients “difficiles à rejoindre” dans cette unité ou ce CLSC?*
- 2.2 Is the health information/education given to patients simple and easy to understand? - *L’information donnée aux patients (information écrite, orale et enseignée) est-elle simple et facile à comprendre?*
- 2.3 Do you think hard-to-reach patients understand it? - *Les patients « difficile à rejoindre » sont-ils en mesure de comprendre l’information qu’on leur donne?*
- 2.4 Would hard-to-reach patients be able to use the information if they chose to do so? - *Les patients « difficile à rejoindre » seraient-ils en mesure d’utiliser cette information (la mettre en application dans leur vie quotidienne) s’ils le voulaient?*
- 2.5 Does it help them become more involved in their health? Does it help patients take responsibility for their health? Does it help them make better-informed choices? - *L’information aide-t-elle les patients « difficile à rejoindre » à s’engager davantage face à leur santé? Est-ce que cela les rend plus responsables de leur santé? Est-ce que cela aide à faire des choix plus informés?*
- 2.6 Do you have anything to add about the appropriateness of health information/education? - *Avez-vous autre chose à ajouter sur la pertinence de l’information donnée aux patients?*

Part 3. The needs of health care professionals

Partie 3. Les besoins des professionnels de la santé

- 3.1** What are your needs when you are preparing written information? (examples: language used, design, translation) - *Quels sont vos besoins lorsque vous préparez de l'information écrite? (exemples: niveau de langue, mise en page, traduction)*
- 3.2** What are your needs when you are teaching patients one-to-one and in small groups? (examples: teaching materials, time allocated) - *Quels sont vos besoins lorsque vous enseignez à des patients individuellement ou en petits groupes? (exemples: matériel d'enseignement, temps alloué)*
- 3.3** Do you need other forms of communication such as visual posters, audiotapes, and videos? If so, please explain. - *Auriez-vous besoin de matériel tel que des affiches, des cassettes audio et des vidéos? Si oui, veuillez expliquer.*
- 3.4** What could the hospital administration do to improve health information and education for hard-to-reach patients? - *Que pourrait faire l'administration de l'hôpital pour améliorer l'information donnée (information écrite, orale et enseignée) aux patients "difficiles à rejoindre"?*
- 3.5** Do you use computers in your work as an educator? If so, explain. - *Utilisez-vous l'informatique pour votre travail en tant qu'éducateur(trice)? Si oui, veuillez expliquer.*

Part 4. The planned Health Literacy Centre

Partie 4. Le Centre d'éducation à la santé

After the Needs Assessment, we plan to set up a new Health Literacy Centre at the hospital for patients. We would like you to dream a bit. What should it be like? How would it work? - *Après l'analyse des besoins, nous désirons mettre sur pied un Centre d'éducation à la santé pour les patients et leurs familles. On vous invite à imaginer, à rêver. On désire savoir ce que vous aimeriez avoir dans ce centre.*

Sub-questions to help along - Sous-questions :

- What should a Health Literacy Centre offer to hard-to-reach patients? - *Qu'est-ce qu'un tel Centre pourrait offrir aux patients « difficiles à rejoindre »?*
- What should be the role of health care professionals? - *Quel serait le rôle des professionnels de la santé?*
- Would the Centre be only in the hospital? - *Est-ce que le Centre serait uniquement à l'hôpital?*
- Would it be in one place in the hospital or in many different places? - *Est-ce que le Centre serait à un endroit dans l'hôpital ou dans plusieurs endroits différents?*
- Would it be run by patients or health care professionals or volunteers or a mix of all three? - *Qui pourrait gérer le Centre? Les patients, les bénévoles, les professionnels de la santé?*
- Would it involve a lot of community resources, community groups? - *Quels devraient être les liens avec les ressources communautaires, les groupes communautaires?*
- Do you see a place for videos, computer programs, drama, etc.? - *Est-ce que vous croyez que l'on devrait avoir des cassettes vidéos, des programmes d'ordinateurs, des pièces de théâtre?*
- Could it involve in-service training for health care professionals to communicate better with hard-to-reach patients? - *Est-ce que l'on pourrait former les médecins et les infirmières à mieux communiquer avec les patients?*

Final question - Dernière question:

Do you have something else to tell us about health information and education of patients? - *Avez-vous autre chose à nous dire sur l'information sur la santé donnée aux patients?*

Appendix 6. Numbers and Demographic Breakdown of Interviews

Numbers

Individual interviews with written questionnaire (30 to 60 minutes)

| | Dialysis | Oncology Hematology | Pre-Op Centre | Other (CLSC) | TOTAL |
|-----------------------------|----------|---------------------|---------------|--------------|-----------|
| Patients | 19 | 8 | 8 | | 35 |
| Caregivers | 1 | 4 | 5 | | 10 |
| Support Staff* | 3 | 2 | 1 | | 6 |
| Health Care Workers† | 4 | 3 | 4 | 4 | 15 |

* Support staff included one patient attendant, one dialysis technician, one head secretary, one clinic coordinator, one admitting officer and one interpreter. We chose support staff members who have a lot of contact with patients and families.

† Health care workers included 10 nurses, 2 dietitians, 2 social workers, and 1 pharmacist. Of the 4 CLSC workers, two were from CLSC Côte-des-Neiges, and two from CLSC Metro Guy.

CLSC informants

The two CLSCs (Metro Guy and Côte-des-Neiges) were interested in our study and very cooperative. They wish to collaborate further on the issue of patient education in the future. CLSC Côte-des-Neiges includes a large research centre specializing in the health of ethno-cultural communities. We were able to interview a Cree interpreter.

Gender

| | Patients* | | Caregivers† | Support Staff | Health Care Workers |
|---------------|-----------|------|-------------|---------------|---------------------|
| Male | 23 (66%) | D 12 | 5 (50%) | 4 (66%) | 2 (13%) |
| | | O 6 | | | |
| | | P 5 | | | |
| Female | 12 (34%) | D 7 | 5 (50%) | 2 (34%) | 13 (87%) |
| | | O 2 | | | |
| | | P 3 | | | |

* This column shows the breakdown of male and female patients across the three hospital units: D = Dialysis; O = Oncology Hematology; P = Pre-op Centre.

† Of the 10 caregivers, 5 were male (of these, two were husbands and three sons of patients) and 5 female (including four spouses and one patient's daughter).

Average age

| | Patients* | | Caregivers [†] | Support Staff | Health Care Workers | |
|--------------------|-----------|------|-------------------------|---------------|---------------------|----|
| Average Age | 63 | D 63 | 55.5 | S 71 | 31.5 | 38 |
| | | O 67 | | C 40 | | |
| | | P 60 | | | | |

* This column shows the average age of patients in each hospital unit: D = Dialysis; O = Oncology Hematology; P = Pre-op Centre.

[†] This column shows the average age of all of the caregivers (55.5 years), and the average age when divided into two groups: S = Spouses; C = Children of patients.

The average age of the patients interviewed is quite high (63). This reflects the fact that there is a higher proportion of hard-to-reach patients among seniors. It also reflects a high average age for all patients in the Dialysis and Oncology Hematology Units. The average age of all Dialysis patients was 61¹¹. The average age of a sample of 37 Oncology Hematology patients was also 61¹². Support staff and health care workers are, by contrast, relatively young.

First language

Patients in all units: 35

| | English | French | Other |
|----------------------------|-----------------|----------------|-----------------|
| Dialysis | 7 (37%) | 3 (16%) | 9 (47%) |
| Oncology Hematology | 2 (25%) | 1 (12.5%) | 5 (62.5%) |
| Pre-op Centre | 2 (25%) | 2 (25%) | 4 (50%) |
| TOTAL | 11 (31%) | 6 (17%) | 18 (51%) |

Other first languages: 18 patients

| | Italian | Greek | Spanish | Cree | Other |
|----------------------------|----------|----------|----------|----------|-------------|
| Dialysis | 2 | | 3 | 1 | Hindi 1 |
| | | | | | Filipino 1 |
| | | | | | Arabic 1 |
| Oncology Hematology | 2 | 2 | | | Hungarian 1 |
| Pre-op Centre | | 1 | | 1 | Cantonese 1 |
| | | | | | Persian 1 |
| TOTAL | 4 | 3 | 3 | 2 | 6 |

¹¹ Taken from a list of patients on May 9th 2001.

¹² Ibid.

Caregivers (10), support staff (6), and health care workers (15)

| | English | French | Other | |
|----------------------------|----------------|---------------|--------------|-----------------|
| Caregivers | 4 (40%) | | 6 (60%) | Italian 3 |
| | | | | Hungarian 1 |
| | | | | Bengali 1 |
| | | | | Punjabi 1 |
| Support Staff | 3 (50%) | 1 (17%) | 1 (17%) | Cree 1 |
| | Bilingual | 1 (17%) | | |
| Health Care Workers | 6 (40%) | 6 (40%) | 3 (20%) | Chinese 1 |
| | | | | Spanish 1 |
| | | | | Vietnamese 1 |

Employment status of patients

Patients in all units: 35

| | Retired | Don't Work/ Stay Home | Disability | Work Outside Home* | Other (N/A) |
|----------------------|----------------|----------------------------------|-------------------|-----------------------------------|--------------------|
| # of Patients | 20 (59%) | 8 (23%) | 5 (15%) | 2 (6%) | 1 (3%) |

* Of the two patients who work, one works full-time, the other part-time.

The large majority of patients are not working outside the home. They are either retired, at home or on disability. This reflects the facts that informants were elderly (average age of 63) and that many of them were very sick (54% on dialysis) and could not work.

Appendix 7. Findings from Individual Interviews

7.1 Patients' Responses (N=35)

Code for each unit

D: Dialysis patients

O: Oncology Hematology patients

P: Pre-op patients

Part 1. Health education needs and current sources of information

Question 1.1

| TYPES OF INFORMATION NEEDED | Dialysis | Oncology | Pre-op | TOTAL |
|---|----------|----------|--------|----------|
| Medical information | 18 | 7 | 6 | 31 (89%) |
| Daily living (e.g., diet, exercise, etc.) | 18 | 6 | 5 | 29 (83%) |
| Information on medication/tests | 17 | 6 | 5 | 28 (80%) |
| How you feel | 7 | 3 | 4 | 14 (40%) |
| Health sites, community | 4 | 5 | 2 | 11 (31%) |
| Help to fill out forms | 1 | 2 | 6 | 9 (26%) |
| Impact on family life | 4 | 2 | 1 | 7 (20%) |
| Getting around hospital | 1 | | 3 | 4 (11%) |

What one Dialysis patient identified as needs:

- All patients need the information and education on dialysis given during the pre-dialysis workshop. This information needs to be repeated later on with clear examples.
- The schedule of physicians, in order to know who is coming when.
- To know the importance of keeping active.
- To combat the sense of depression and anger, the feeling of being victims. They need to move beyond the complaining mode that affects the body and blocks learning.
- To learn to take drugs and record symptoms.
- Information about how to associate side effects with how you feel.

There is a need to facilitate patient-to-patient information transfer.

- Families need the same information as patients in order to be able to support patients.
- Remember that patients will be on dialysis for years. It does not matter if they do not understand the necessary information right away, if they only understand after 6 months. They have a lot of time to learn.

Question 1.2

a) Regarding written information

14 (40%) found the written information they received useful. 6 (17%) did not. 5 (14%) said they did not read it because they cannot read English or French, one said he does not like to read, and 7 (20%) said their caregiver took responsibility for reading.

Unit-specific feedback on written information

7 Dialysis patients found useful the white binder entitled *Living with Kidney Disease* produced by the Canadian Kidney Foundation (French version is *Vivre à sa façon*).

3 Oncology patients found useful the pink booklet on chemotherapy produced by the Canadian Cancer Society.

4 Pre-op patients found useful one of the two handouts given to all Pre-op patients: “Day Surgery” or “Preparing for Surgery”.

N.B. Some Dialysis patients never received the binder and so could not comment on it. Either they arrived at the Dialysis unit before the binder was produced or they came into the unit following an emergency and did not attend the pre-dialysis workshop (the binder is given during this workshop).

b) Regarding oral communication

15 (43%) said they were satisfied with the oral information given to them by doctors, nurses and other health care professionals. 20 (57%) of patients interviewed are not satisfied. Satisfied patients included 8 D, 3 O and 4 P.

Problems identified by patients:

- Language barriers: Nurses and doctors do not explain well, they do not explain anything in Spanish; patient does not understand much English, only gets limited explanations.
- Communication is a challenge when daughter (interpreter) is absent.
- Doctor does not say everything you want to know.
- Doctor does not talk enough, gives very little information.
- Either nurses and doctors do not tell you anything, or, for small problems, they give you too much information in scientific terms.
- Different staff give you different answers.
- Nothing is really useful in terms of managing specific situations.
- Had a session on what to expect from dialysis but it raised more concerns than anything else.
- Lack of time for patient education, “if you don’t speak up, you get left behind.”
- Some nurses are too rough with patients, too hard.

Advice given by patients (paraphrased but respecting their words):

- Be sincere, do not avoid tough questions, do not avoid information that can worry people or else you have problems later on, tell the truth to caregivers, this is crucial to develop trust; Patient wants information up front, wants to get all the information. So “say why and what it is”. Do not keep anything from patient; if the patient is wise, he will know what there is to know eventually. ° Say everything, tell the truth, say everything about the secondary effects. Come out straightforward, do not beat around the bush.
- Stay clear of medical jargon. Be clear in laymen terms. We need crystal clear information. Use plain language, not medical jargon.
- Do not speak too quickly. Do not be in a rush. Take more time, listen and try to comfort patient.
- Listen to patients. We want two-way clear communication. Listen to our needs, our questions and give answers; doctors: do not be dismissive
- MDs and RNs are always keen to tell what you should do or what you are not doing right, they should also know when to congratulate a patient for what he/she does right.
- Show respect. Take into account the illness, the sensitivity of patients. Do not treat us like six- year olds (some do but not all). Forget your emotions, your prejudices, learn how to interact and deal with long-term patients.
- Get to know your patient’s level of learning. Ask patient to repeat the key points.

c) Regarding other sources of health information

| Other Sources of Health Info | Used by Patients? | | Comments by patients |
|---------------------------------------|-------------------|--------------------|---|
| | YES | NO | |
| Health video | 20 (57%) | 14 (40%) | <ul style="list-style-type: none"> Gives general information, useful, explains well, good introduction Some parts of the dialysis video are not realistic (man mowing his lawn, patient smiling all the time), not enough details, not useful because not in patient's language or because patient is blind. |
| | D 14 P 6 | D 5 O 7 P* 2 | |
| Group discussions with other patients | 4 (11%) | 27 (77%) | <ul style="list-style-type: none"> Useful to hear what others have to say, good testimonies, others ask questions you don't think of asking and new opinions, you learn from their experience, good to know what may lie ahead. Simply talking to another patient is comforting. Learns more from other patients than from doctors/nurses. Would have benefited from peer coaching/support but never had that opportunity. Cannot really participate because of language barrier (Spanish) but can relate to attitudes, emotions of others, sharing of experiences. Experiences are so different you cannot expect to learn a whole lot about your own specific needs/situation. Informal meetings of dialysis patients before treatment Better in small groups of 4 to 8, not large classes. |
| | D 3 P 1 | D 12 O 8 P 7 | |
| Workshop in CLSC or elsewhere | 1 (3%) | 29 (83%) | <ul style="list-style-type: none"> Prefers to do learning while at hospital |
| | D1 | D 14 O 8 P 7 | |
| TV or radio shows | 15 (43%) | 5 (14%) | <p>*This question was added during the course of the Needs Assessment so it was not asked of all patients.</p> <p>Examples of TV shows: <i>Pulse Medical Report</i> (ch.12), show on the Discovery Channel, Italian health shows, <i>Découverte à Radio Canada</i> (Dim.18h30), Canal <i>Vie</i> on the health / nutrition of women and children, Operating Channel.</p> <ul style="list-style-type: none"> The show <i>Découverte</i> gave excellent information on the immune system, cancer and transplants. Patient said the show helped him and his caregiver become more involved in his health treatment. |
| | D 7 O 3 P 5 | D 1 O 3 P 1 | |

* The two Pre-op patients had not yet seen the video.

Question 1.3 If hospital signs are clear enough

3 (9%) patients said no, including one who could not read and one who faced a language barrier. This question and the next are analysed in Section 2.1 of this report.

Question 1.4 If forms are easy to fill out

6 (18%) patients said no, they need help to fill out the forms. This number includes 2 Dialysis and 4 Pre-op patients. The reasons given were because the patient does not read/write, or because of a language barrier.

Part 2. How the patient learns best

2.1 Learning preferences*

| How patients learn best | Dialysis | | Oncology | | Pre-op | | TOTAL | |
|-------------------------------|----------|----|----------|----|--------|----|----------|----------|
| | YES | NO | YES | NO | YES | NO | YES | NO |
| Verbal explanation | 16 | 2 | 7 | | 8 | | 31 (94%) | 2 (6%) |
| Alone with a teacher | 14 | 4 | 6 | 1 | 8 | | 28 (85%) | 5 (14%) |
| Watching videos | 12 | 6 | 4 | 3 | 7 | 1 | 23 (70%) | 10 (28%) |
| In groups with other patients | 12 | 6 | 2 | 6 | 8 | | 22 (65%) | 12 (35%) |
| Reading | 12 | 4 | 4 | 4 | 5 | 3 | 21 (66%) | 11 (31%) |

* In this table, YES indicates the number of patients who like to learn in this manner, and NO the number who do not like or use this method.

Additional responses/comments

Do you like to be alone with a teacher?

- 2 patients said that a family member must be present.

Do you like to be learning in a group with other patients?

- One patient said he does not want to hear about other patients' problems, he has enough dealing with his own.

Later in the questionnaire, we asked **what makes a patient comfortable when they are learning in a group** (Question 2.2). Those patients who like to learn in a group answered that they liked small groups because of the high level of participation. They can learn from other patients' experiences, and share concerns, life experiences, feelings and reactions, as well as information. They like being able to ask questions and to learn from others' questions. Patients said it is reassuring to see you are not alone in your situation. Also, you can help others in the group.

Do you like to read information?

- Of those who liked reading, 3 read in a language other than French or English, 1 reads very slowly, 1 reads with a dictionary, and 1 reads with the family member.

Do you like to have someone explain it to you verbally?

- A few patients, including two blind patients, said this is the best way for them to learn.

Do you prefer to ask a doctor, nurse, or someone else (e.g., patient, family member, friend)?*

| # of Patients / unit | Doctors | Nurse | Someone Else |
|----------------------|----------|----------|--------------|
| Dialysis | 15 | 13 | |
| Oncology | 7 | 4 | |
| Pre-op | 7 | 3 | |
| TOTAL | 29 (83%) | 20 (57%) | 4 (11%) |

* Figures show the number of patients who said they would ask questions of the group indicated.

Many patients answered that they prefer to ask both doctors and nurses. Only four patients answered that they prefer to ask someone else.

To learn about health, would you rather be in the hospital, a CLSC, community centre, home or elsewhere?

| | Hospital | Home | CLSC | Community | Other |
|-----------------|----------|----------|--------|-----------|--------|
| Dialysis | 10 | 5 | 3 | | 3 |
| Oncology | 5 | 4 | | | |
| Pre-op | 1 | 4 | | 1 | |
| TOTAL | 16 (44%) | 13 (36%) | 3 (9%) | 1 (3%) | 3 (9%) |

Additional responses/comments

Prefer the hospital

- They are comfortable in the hospital. They are already there for treatment, and it is where you find the medical expertise.
- One patient said that learning about health is all you have to do at the hospital, so you can concentrate on that.
- One patient said he wants to keep the sickness separate from his private life, and learning at the hospital helps him to do that.

Prefer learning at home

- Some patients said that home is a better place because they can relax, have more time to think, analyse and note questions, and it is easier to read about health.
- Home is quieter and they feel more at ease, less nervous than in the hospital. Family members are there to answer questions.

Prefer other settings

- To learn about health, 3 Dialysis patients prefer to be in a CLSC;
- 1 Pre-op patient preferred to be in the community clinic (Cree patient, clinic in northern community); and
- 3 Dialysis patients prefer to be elsewhere (in northern community, in day centre, in cyberspace).

Do you prefer to practice skills alone or in front of a health care worker?

- 21 (64%) of 35 patients prefer to practice in front of a health care worker if they have a skill or a health procedure to learn. 4 (11%) prefer to practice alone. 10 patients did not answer the question.

What makes a good teacher?

Patients said (paraphrased and grouped):

- ***Someone who is qualified, who knows about health:*** professional, extremely experienced, gives complete information, can explain from the beginning until the end, well trained, knows subject well, can answer questions, high level of expertise, speaks different languages (for example, Cree).
- ***Someone who is a good communicator and listener:*** explains well, outgoing, ability to use common language and use analogies, takes time to explain, explains slowly and in plain language, readiness to answer questions along the way and right away; explains clearly and calmly, can keep our attention, good animator.
- ***Someone who values positive human relationships:*** accessible, sincere, makes you feel at ease, understanding, compassionate, has good manners, patient, attentive, caring, relaxed, friendly, human qualities of honesty, friendship, respect and loyalty, is himself or herself.
- ***Someone who is empathetic:*** says things as they are, can put himself or herself in the place of the patient, understands that the information is crucial for patient, takes time one-to-one for questions and respects the patient's rhythm, likes what he or she is teaching, will teach outside the specific subject area.

It is better if the teacher is someone with experiential knowledge, in this case first hand knowledge of the illness, for example a doctor following a dialysis treatment. Patients added that, of course, this was very unlikely.

Do you use a computer?

- 23 (66%) do not use a computer.
- Of the 6 (17%) patients who say they do, 2 do not use it to learn about health. This is analysed more fully in Section 2 of the final report.

Part 3. The Health Education Centre

The key question on the Health Education Centre was generally posed open-ended to patients (only if they seemed “stuck” would the researchers offer possible answers). Some patients commented on the location of the Centre, some on the activities and programs, some on its internal organization. This explains why the numbers regarding suggested activities do not add up to the total number of interviewed patients.

What patients said they would like*:

| If offered at the Health Education Centre | D | O | P | Comments |
|--|----------|----------|----------|---|
| More and better written information | 5 | 4 | 3 | Would like information in Cree, in Spanish and in Braille. |
| Health videos | 8 | 4 | 5 | One patient’s first language is Persian but would like video in French to learn terminology in French. |
| Small classes | 2 | 3 | 2 | With demonstrations and small presentations Someone who can answer questions weekly Q&A sessions with MDs |
| Patient group discussions | 3 | 2 | 3 | Discussions should be planned for when patients come for their treatments |
| Computer programs | 8 | 1 | | Can print out the information |
| Drama | | 2 | | |
| Audio tapes | | 2 | | |

* Numbers indicate how many patients said they would like/use such a service.

5 patients (2 from Dialysis; 1 Oncology Hematology; and 2 Pre-op) said they **would NOT use** a Health Education Centre.

Reasons were:

- One already feels well informed;
- One likes to learn on his own;
- Two have no interest in learning more;
- One does not want more information;
- One added that he is afraid because it will remind him of his illness: “The less I know, the better I feel”.
- One wants to talk about the illness the least possible.

Additional comments/responses

Location of Health Education Centres

Patients said that the Education Centre should be very close to the unit in a clearly allocated room easily accessible so they can use it while they are waiting for their treatment. All the information / services should be in that one place.

Who should take care of the Health Education Centre

Interviewed patients saw specific roles for health care professionals, volunteers and themselves.

Role of health care professionals:

- One professional managing the Centre;
- Co-ordination
- Resource people;

Role of volunteers:

- “Staff” the Centres, with specific roles in programming;
- Run the Centres, supervised by a health care professional;

Role of patients and their families:

- Give advice on information and education needs;
- Give input on what it offers, how it works;
- As equal partners in learning: families would use it just as much as patients: same access/same reasons.

Only four patients mentioned that there should be **training** offered at the Health Education Centre for doctors, nurses and health care workers. Some mentioned that this should not be a priority since staff members are already doing a good job.

Other comments by patients on the Health Education Centre

- It should be an organised space offering thematic activities.
- It should focus on visual information.
- It should be a library type of place.
- It should be somewhere to sit down, relax and have lots of time. A place where you can talk and ask questions in a relaxed, no stress atmosphere.
- Two principles to respect: KISS: Keep it short and simple, OHIO Only handle it once.
- A centre could help sift through “hear-say” (comment from Dialysis patient).
- A centre should be constructively run, a trend-setter. There should be advance public relations with a very clear agenda so patients know exactly what will be happening, what is going to be said and if they need/want it.

7.2 Caregivers' Responses (Family Members) (N= 10)

Code for each unit

D: Caregivers of dialysis patients

O: Caregivers of oncology hematology patients

P: Caregivers of patients using pre-operative centre

Part 1. Health education needs and current sources of information

Question 1.1

| TYPES OF INFORMATION NEEDED | Dialysis | Oncology | Pre-op | TOTAL |
|---|----------|----------|--------|---------|
| Medical information | 1 | 4 | 4 | 9 (90%) |
| Daily living (e.g., diet, exercise, etc.) | 1 | 2 | 5 | 8 (80%) |
| Information on medication/tests | 1 | 2 | 4 | 7 (70%) |
| How you feel | 1 | 2 | 4 | 7 (70%) |
| Health sites, community | | 2 | 4 | 6 (60%) |
| Impact on family life | 1 | 2 | 2 | 5 (50%) |
| Help to fill out forms | | 2 | | 2 (2%) |
| Getting around hospital | | 1 | | 1 (10%) |

Other needs and comments:

- Need to know more about how and when to take medication; we learned through trial and error not to take medication before dialysis.
- Need more information about how treatment is working.
- Wants to know how the different specialists interact, how they share information about the patient and when they will meet the patient.

Regarding navigation and forms to fill out, answers to questions 1.3 and 1.4 confirmed that these needs were less important for this group. All ten caregivers said the signs were clear and three caregivers needed help with forms.

Question 1.2

a) Regarding written information

8 (80%) found it useful. (1 D; 2O; 5P); 2 (20%) did not read it. (2D)

Comments:

- very useful, very complete
- useful if patient has fever, useful for side-effects, did not have to call centre
- translates many points to his father in Italian, repeats a second time the most important points;
- would be good to have documents in Italian; his father would be able to read and understand them.

b) Regarding oral communication

8 (80%) said it was good. (1D 2O 5P)

Comments:

- Many caregivers commented on the good relationship with nurses.

Advice:

- Give information a little differently, so that it is not so much a shock.
- Doctors: take more time to explain and talk to patients.
- Use simple words, give examples with drawings.

c) Regarding other sources of information

| | YES | | NO | | Comments |
|---|--------|--------|-------------|-------------|--|
| Videos | D P | 1 3 | O 6 | | Video was very good, informative for the son but his father did not understand anything in English, it would need to be in Italian. Caregiver translated parts of it. |
| Group discussion with other patients | D | 1 | O P | 4 5 | |
| Workshop in a CLSC | | | D O P | 1 4 5 | |
| Information from TV or radio | O | 4 | D P | 1 1 | *This question was added during the course of the Needs Assessment so it was not asked to all caregivers. Program on cancer useful. Show on new drug, not for her husband's cancer. Information on health but false hopes ex. transplantation Medical shows on canal <i>Vie</i> |

Part 2. Health Education Centre

We asked the caregiver if he or she thought that the patient would want to participate in these activities/programs.

| If offered at the Health Education Centre | D | O | P | Comments |
|--|----------|----------|----------|---|
| More and better written information | | 1 | 2 | <ul style="list-style-type: none"> • Would like written information in Italian, Bengali, Punjabi • Suggestion: small booklets about different illnesses (main points); you can read while you are waiting, you can recognise symptoms yourself (prevention). |
| Health videos | | 2 | 4 | <ul style="list-style-type: none"> • Would like videos on specific surgery, e.g. cataract eye surgery • Centre could lend out health videos for older patients in Italian e.g. video on bacteria, food spoilage, hygiene. |
| Small classes | | 2 | 1 | |
| Patient group discussions | 1 | 2 | 3 | <ul style="list-style-type: none"> • One caregiver suggested beginning with an information session, and as patients become more at ease with one another and more trustful, to transform it into a patient discussion group with more participation. • The language barrier would prevent some patients from participating. |
| Computer programs | 1 | 2 | | <ul style="list-style-type: none"> • Would want to use a computer program with the help of a volunteer |

Caregivers told us that **four patients would not want to use a Health Education Centre.** One patient does not want to discuss her illness (cancer) with others nor hear about it from others. One caregiver said his father would not be interested because of his advanced age, his low level of education and because his concern about his illness blocks learning.

7.3 Support Staff's Responses (N=6)

Questions asked by patients

Support staff in the three units handle all kinds of questions from patients, depending on their role. One technician says that patients sometimes test him with questions, to make sure that he is competent. Support staff refer patients to nurses and doctors when questions are related to health. According to one informant, doctors do not give enough required information to patients. Because of this, she must handle many questions by patients. According to this same informant, patients are afraid of doctors, do not ask them questions and never complain when the doctor is late.

Needs of hard-to-reach patients

Most informants mentioned two obvious needs: Some patients face language barriers so they **need an interpreter or a family member** to translate. Patients need to come with family members who can help with the visit in general and the health information (translation or explanation).

One informant said that because of the difficult working environment, some nurses do not answer the needs of patients. They experience frustration and communication gap with some hard-to-reach patients. These patients **need to feel welcomed and respected**, and they need positive non-verbal communication.

One informant said that patients **need the medical staff to be listening**. Staff members need to stop 3-4 seconds and listen attentively to patients who always manage to make themselves understood through signs and movements if they do not speak English or French.

One informant said that patients are sick people and vulnerable. They **need reassurance, hope, love, support and compassion**. They need to know "what is going to happen to me?" The **spiritual** need of patients is totally lacking according to the informant. There are no services offered for patients of Muslim, Hindu, Buddhist or Baha'i faith. The psychiatrist only comes when there is a crisis.

According to one informant, an important need of all Oncology Hematology patients is to have a **sense of family in the clinic**. Patients like to feel they are accommodated. When it was a smaller clinic there was a strong sense of family. This sense is slowly coming back.

Patients from the pre-op clinic **need basic explanations repeated** (where to go next in the hospital, the order of tests, how the operation will unfold, etc.). Because of stress and anxiety they do not pay attention when they get the information. Staff members talk too fast and patients do not follow. They are not really listening to the information. Often "nerves" rather than age makes it harder for them to learn.

One informant mentioned that **patients from different cultures have different needs**. For example, Inuit people are stoic about pain and are very trusting. They do not demand a lot of information from medical staff. One informant identified some of the cultural differences experienced by Cree patients. These patients generally talk less than non-Cree patients, they are less expressive and give short answers. Because of this, doctors and nurses sometimes think they do not understand. Because so little written information is available in Cree, these patients must rely on oral information and their memory. This is a very big challenge and a limit to patient education. Cree patients sometimes do not feel comfortable in Montreal and do not know about the medical terms or procedures. They need someone to be with them, to explain what is being said, to help with appointments and to get medication. Their most

obvious (but difficult to answer) need is to have medical services as much as possible in their northern communities. Cree patients are more comfortable in their village with their families and friends.

How we can improve health information and education

- **Lend patients short videos in other languages** (a generic video with audio tapes in different languages). Patients could watch it at home as many times as they want and come back with their questions to ask nurses or the doctor.
- **Use more testimonials.** We could show videos of a patient who has gone through successful treatment. Patients would hear not only the information but would get the experience and the hope.
- **Show more what the operating room looks like** but not bloody scenes of operations. Patients do not want to see their operation, but they want to be kept aware.
- **Have staff members who are more culturally sensitive.**

One informant proposed a **simple communication tool** that would break down language barriers: Dialysis patients could use a one-pager that would show with pictures all their basic needs (water, blanket, crackers, lunch, etc.). Anyone would be able to use it.

One informant cautioned that even if the information is very simple, we will still not reach some hard-to-reach patients.

Advice on the Health Education Centres

About written information

- There could be more written information (culturally-sensitive information pamphlets) e.g. in Cree; however, older people do not read a lot; younger people can read English more; and pamphlets tend to be thrown away.
- We should produce booklets with attractive and colourful cartoons (focus on visual), showing regular people in everyday life situations. We could produce one issue per month, e.g. on an aspect of dialysis.
- We could develop puzzle games with questions and answers.

About computer programs

- Computer programs are better for nurses than for patients. Nurses will not have time to help patients with it.
- Computers are not attractive for older patients, but may be for younger patients.
- Well-developed computer program could show how new treatments work. This could be part of the patient's compulsory orientation. It could help to ease fear. If patients know more, this can lessen anxiety levels.
- Offer computer programs with volunteers from the person's community ex. Greek community.

About drama

- Drama is not a good idea: too much of an effort, dialysis patients are older people, too hard for them to role-play, too tiring. Drama is good for kids, but not for these adults.
- Drama could work very well with Cree patients, role playing is a great idea for them. Cree people like support groups; they are a bit like their small close-knit communities.

About other ways of learning:

- Focus on visual and videos.
- In the Dialysis unit, take advantage of the TV network to have a channel with health information.

About managing the Centre

- It is important to have human contact in the Centre. The staff could be made up of volunteers and former cancer patients (ex-patients who are doing well).

7.4 Health Care Professionals' Responses (N=15)

Part 1. What you know about health literacy and low-literate patients

1.1 For most informants, low literacy means:

- People who have problems reading and writing;
- People who cannot follow simple directives, who do not understand oral and written information;
- A social worker answered that low literacy means isolation, dependency, abuse and discrimination.

1.2 Informants said that low health literacy means:

- People with limited knowledge about their body, who lack insight into their health;
- Patients who have difficulties understanding health information such as side effects, why he or she needs to take this medication. They have problems with compliance.
- People who are not medically aware of their needs, who do not know what is best for them. They cannot make decisions or solve problems regarding their health. They take a less active role in their care than other patients.

1.3 Informants describe low-literate patients the following way:

- Patients who will not read in front of a nurse, who will say they understand everything, who will say they will read it at home. They are very good at hiding the fact that they cannot read. They will use different excuses such as « I forgot my glasses »;
- Disadvantaged or poor patients, older patients, patients who smoke and have bad health habits, - patients who live in poor neighbourhoods.
- Patients who are non-talkative and very shy, or in some cases, who talk all the time and reveal inappropriate personal details.

One social worker said that low-literate patients are less articulate, less forthcoming with information and less clear in their storytelling. It is harder for the social worker to understand their story.

1.4 How health care professionals communicate with and teach low-literate patients:

(interviewed health care professionals include two nurses, one social worker and one dietician from two CLSCs)

- Stick to the most crucial, minimal (“life and death”) information. Repeat key points to patients (up to three times). Give only the most important information to avoid overload.
- Explain clearly, one step at a time. Follow a more structured pattern to give the information (steps 1,2,3...).
- Say it in the most simple way possible, adapt the level of language.
- Use key words ex. cereal, dodos, and use very precise guidelines, for example a feeding schedule. Give practical information, for example where to find baby cereal in the supermarket.
- Ask patients questions to check if he/she has understood key points. This can also be done by phone or during another home visit. Make the patient repeat it back.
- Ask often if patient has understood, ask if patient has any questions.

For some informants, teaching hard-to-reach patients takes less time. Less information is given as the health care worker tries to avoid overload. The principle is that less health information makes it easier to understand; more detailed information makes it more complex. For other informants, it takes more time since there is the need for a lot of validation. The teacher must make sure that the information has been understood. One informant uses an approach based on the principles of adult education. She begins by asking patients what they want to know. She starts from their questions which usually causes patients to want to know

more. She then teaches what they have to know and ask them to repeat it. Finally, she identifies a member of the family who can read and makes sure that the person gets the information in writing. This approach takes more time than only giving minimal information.

Informants use different strategies regarding written information. Some put aside written information while others try to find potential users. Informants suggested these strategies:

- Focus on oral communication. Do not give written information to patients. Do not ask them to write anything. Work with the family, involve a family member.
- Say you will give them written information so they do not have to worry about writing anything.
- Use written information only as a support to the oral. Ask who in the family can read English or French.

How do you know if the patient is low-literate?

- Some informants ask patients to read something or ask them if they want written information.
- One informant asks patients “Can you understand my writing?” and asks them to read what she wrote, i.e. the key information that patients need to know. This is an indirect and more respectful way of checking if they can read and if they can use what she wrote down.
- One informant writes in the file “doubt patient understands health information” so that the whole medical team is aware of the issue.

Part 2. What health care professionals think are the needs of hard-to-reach patients

2.1 The education needs of hard-to-reach patients

The answers, while often referring to a specific unit, can be grouped into three categories:

Need for specific information

- For Dialysis: more complete information (and better documentation) for patients to make an informed choice e.g. between peritoneal dialysis and hemodialysis;
- For all Dialysis patients to attend the pre-dialysis clinic or a complete teaching session;
- For Oncology Hematology patients: need to know why the treatment is done, about the side effects, how to take the anti-nausea medication, when they need to call for emergencies and what to do if they have a fever;
- For Pre-op patients: need advice and information to find their way in the hospital; Pre-op staff take a lot of time to explain how to get to other parts of hospital;
- For CLSC clients: education on common health problems, contraception and vaccines.
- For CLSC clients who are immigrants or refugees: information on how the Canadian health system works. For example, as one informant explained, it can be difficult for these clients to understand that someone will call later to make an appointment, or that a card might be sent with the appointment information. It can make them very insecure. Some clients cannot understand a message left in English or French. They prefer to be given an appointment while they are at the CLSC.

Need for better adapted teaching material and hand-outs for patients

- For Dialysis: better and easier material on peritoneal dialysis; visual material, ex. renal nutrition educational tool; need for simpler information using pictograms; need for information using colour codes, e.g. calendar with colour on days of medication;
- Material translated in the languages of patients and caregivers;
- Material in plain language;

- Pre-op Centre: updated written material. Documents given to patients must be redone, corrected, updated, written in plain language, etc. This was an urgent need identified by the three nurses.

Need for a better, more thorough teaching process

- More repetition, more follow-up, more validation that the information has been understood; need for the nurse to call up a few days after the treatment (for Oncology Hematology patients) to check that all is well and that patient has understood key points;
- For Dialysis and Oncology Hematology: a nurse to follow the same patient to have continuity and better follow-up;
- A family member to be involved in the teaching process; this is crucial for hard-to-reach patients who do not read and who face language barriers. It will also help patients in general since the family member can assist with the patient’s care;
- For Oncology Hematology : teaching to be done on different days and for teaching to be done in small doses, not all at once. Currently, patients receive the teaching during the first treatment when they are super-anxious and overwhelmed with information. One nurse said that probably 75% of the information does not get through to patients.

For one informant, the heart of this issue is that health care professionals take for granted that patients have understood the health information. Nurses and others must drop this assumption and take the time needed for validation.

2.2 We asked if the health information / education is simple and easy to understand

Health care professionals were divided on this issue:

| | Dialysis | Oncology | Pre-op | CLSC | TOTAL |
|-----|----------|----------|--------|------|---------|
| YES | | 2 | 3 | 3 | 8 (53%) |
| NO | 3 | 1 | | 1 | 5 (33%) |

- 2 of these informants did not answer.
- Some informants gave specific examples of complicated information (a hand-out given to Dialysis patients for a 24-hour urine collection); some said they try to make it simple but the result is not always appropriate.

2.3 We asked if hard-to-reach patients could understand the health information

| | Dialysis | Oncology | Pre-op | CLSC | TOTAL |
|---------|----------|----------|--------|------|---------|
| YES | 1 | 1 | 1 | 2 | 5 (33%) |
| NO | 1 | 1 | 2 | | 4 (27%) |
| YES/NO* | 3 | 1 | | 1 | 5 (33%) |

* 5 (33%) said “some do, some don’t”.

- 1 did not answer.
- Interviewees are aware that some hard-to-reach patients do not understand the health information given to them, either in writing or orally.

2.4 We asked if hard-to-reach patients would be able to use this information if they chose:

| | Dialysis | Oncology | Pre-op | CLSC | TOTAL |
|--------|----------|----------|--------|------|---------|
| YES | 4 | 1 | 1 | 3 | 9 (60%) |
| NO | | 1 | 2 | | 3 (20%) |
| YES/NO | | | 1 | | 1 (6%) |

- 2 did not answer.
- One informant said that half the patients are very conscious of their health and do everything by the book. Many patients will do what they are told by someone in a position of power. The other half do not care about their health but will do the strict minimum.

2.5 We asked if the health information given to patients helps them become more involved in their health, make more informed choices, take more responsibility for their health.

| | Dialysis | Oncology | Pre-op | CLSC | TOTAL |
|--------|----------|----------|--------|------|---------|
| YES | 3 | 1 | 1 | 1 | 6 (40%) |
| NO | 1 | 2 | 2 | 1 | 6 (40%) |
| YES/NO | | | | | (%) |

- 3 did not answer.
- One informant explained that most people do not change: if they were engaged in their health before becoming ill, they are after (having cancer, being operated, coming to the hospital for their treatment) and if they were passive about their health before, they will be after.
- Some informants believe that most patients want to make healthy changes to their lifestyle. Receiving health information and education can begin a process of patient education and involvement.
- Many informants answered that this is the goal, what they are trying to achieve with patients.
- One social worker commented that having choices is valued in our culture, but in other cultures, it creates insecurity and fear.

Part 3. What are the needs of health care professionals as educators of hard-to-reach patients?

3.1 Regarding written information

- Need to have written material in Italian, Greek, Cree, Spanish, etc. on basic information and what to do in an emergency.
- It is impossible to translate everything and the list of languages is long. Is it worthwhile and feasible to translate documents into Chinese, for example? We need to consider all the aspects, including cost.
- Better cross-cultural knowledge
- Need simpler material, better designed, well presented, colourful, pamphlets in plain language with large font. Pamphlets from pharmaceutical companies are useful but not always in plain language.
- Need for specific written information tools to give to Dialysis patients, e.g. “How to take care of your fistula”, “How to take care of your catheter”, better document “Urine collection 24 hours”

3.2 When they are teaching one to one and in small groups

The majority of informants (9 or 60%) indicated that they would like to have more time to assess the literacy and comprehension level of patients and to teach hard-to-reach patients (including time for validation). Some informants said they already simply take the necessary time. A nurse said that an important principle was that health care workers cannot predetermine the time needed to teach a patient since you have to know the patient's needs to do this.

A few health care professionals would like more quiet space allocated to teaching. Currently, the lack of space and intimacy often distracts patients from learning. Also, nurses need time to meet among themselves and maximise the quality of teaching. There is a need for uniform teaching by all nurses who educate patients.

3.3 The need for other teaching tools such as posters, audio-tapes and videos

11 (73%) (2D, 3O, 3P, 3 from the CLSC) said they need posters for teaching. These posters can be very effective and everyone can understand them. Patients will remember them better if they include a comic element.

10 (66%) (2D, 3O, 3P, 2 from the CLSC) said they need videos for teaching. According to informants, videos can be very useful for a cross-section of people. Health care workers need videos to lend to patients who can watch them at home with their family. Nurses can follow up with questions & answers the next visit. Because of the time and cost of producing videos, it would be helpful to find good videos from other hospitals and health centres. Specific content themes were mentioned: heart video, orthopedic video, chest tube video, video on pain management, video on taking care of incisions, video on birth and breast feeding, video on cholesterol, video on the Canadian nutrition guide, video on diabetes.

5 (33%) (3O, 2P) said they need audio tapes for teaching so patients could listen and then ask questions.

Dialysis staff talked about the need for making better use of the TV system (each hemodialysis patient has his or her own TV monitor). Patients could learn about different aspects of dialysis from an in-service channel while they are being treated. This could be highly effective because there is a captive audience. One informant concluded that the ideal would be to pick and choose among a variety of teaching tools and materials what is most appropriate for a particular patient.

In terms of process, hard-to-reach patients should be screened by nurses and put on the priority list to see the pharmacist. This would avoid having them miss their meeting and not seeing the pharmacist. It can be difficult for the pharmacist to give the key information to a hard-to-reach patient over the phone. And it could be a life or death issue, e.g. telling them about the need to stop aspirin 7 days before the operation but continue the cardiac medication.

3.4 What could the hospital administration do to improve patient education

Interviewees identified the need to allocate

- More human resources: more nurses could mean more time to assess and teach hard-to-reach patients.
- More financial resources: budgets for teaching tools, translation into other languages, rewriting documents into plain language, training health care workers, buying videos and visual material.
- Two interviewees identified the need for a hospital-wide plain language policy.

The staff interviewed at CLSC Côte-des-Neiges said that their CLSC already does a lot for hard-to-reach patients; this CLSC, the largest in Québec, is the provincial leader on the topic of health of ethno-cultural minorities.

3.5 If they used a computer in their work as health educators

9 (60%) (2D, 3P and 4 CLSC) said they use computers in their work as health educators, but some said they do not like the Internet.

6 (40%) (2D, 3O, 1P) said they do not.

Part 4. Advice of health care professionals about the Health Education Centres.

| If offered at the Health Education Centre | D | O | P | CLSC | Comments |
|--|---|---|---|------|---|
| More and better written information | 1 | 1 | | 1 | Offer a library of resources. E.g. for Dialysis patients: <i>Renal Link Newspaper</i> , newsletter AGIR (PQ), <i>Family Focus and Renalink</i> (from USA National Kidney Foundation). These are good materials that look at psycho-social and daily living issues, recipes, etc. |
| Health videos | 2 | 2 | 2 | 2 | Dialysis patients will listen to TV if video is well done and interesting. |
| Small classes | | | 1 | | After watching a video, they can ask questions to nurses. |
| Patient group discussions | 2 | | 1 | | We should offer the opportunity and try it. Male patients will not want to come, they are less at ease in a group, less interested in participating (another informant disagreed with this). |
| Computer programs | 1 | 1 | 3 | 2 | The only chance for many patients to use a computer; Can offer individualised education, for example program on specific surgery with the choice of language, patient can ask questions of the health care worker after viewing. Can offer information in plain language accessible by anyone, health care worker serves as guide, does wrap-up according to level of knowledge of each patient. Role of volunteers is very important. |
| Training for health care workers | 3 | 3 | 1 | | To update teaching skills Acquire techniques on how to reach hard-to-reach patients Presentations by experts in adult education Need training in plain language writing and oral communication. |

Other advice:

- Location: each department should have its own Health Education Centre.
- Make the Centre very user-friendly, accessible, encourage patients to use it, use word-of-mouth to promote it.
- Make visiting the Centre compulsory, after patients have done the Pre-op visit.
- Dialysis and Oncology Hematology patients could learn while waiting for their treatment, to meet the doctor, or for their blood test results.
- Think of the needs of patients with children and offer a place for children to play.
- Hospital units and the two CLSC should collaborate in setting up and running the Health Care Centres.
- There is a need for translators; it is a question of life and death for some patients to understand what is said to them.
- Use games such as *Snakes and Ladders* to learn about health, games with questions, this is an enjoyable and good way to learn, a lot of material already exists.
- Drama would not work; patients are too shy, too self-conscious.

Appendix 8. Findings from Focus Groups

45 informants participated in one of seven focus groups as follows:

7 Focus groups (45 to 60 minutes)

One with Dialysis patients (included 8 patients, 1 caregiver)

One with Dialysis health care workers (8 nurses)

One with Oncology Hematology patients (6 patients)

One with Oncology Hematology caregivers (7 caregivers, 2 patients)

One with Oncology Hematology health care workers (7 nurses)

One with health care professionals of the Patient Education Sub-committee of the Practice and Quality Improvement Council (PQIC) (5 health care workers, 1 nurses' librarian)

Input from participants in the focus groups is written in italics.

Dialysis unit

Focus group with Dialysis health care workers

8 nurses participated including 2 from home dialysis. We explained clearly what we mean by hard-to-reach patients. Answers are very specific to the unit.

Question #1: What are the needs of health care workers who inform and teach hard-to-reach patients? We are looking at the needs of nurses as educators.

Under three headings: written information, oral communication, other materials or teaching tools.

- **Written information (with oral explanations)**

- *Hand-outs for patients:*

- *“How to deal with and control high potassium, high sodium”*

- *“How to deal with and control weight loss”*

- *use diagrams and visuals such as happy face, sad face*

- *Bilingual information sheets in plain language for patients:*

- *“How to take care of your PD or jugular catheter”*

- *“How to take care of your fistula”*

- *Information on nutrition for patients: foods to stay away from*

- *Information for new patients:*

- *what to expect for the first dialysis*

- *insertion and care of the catheter*

- *control of fluid intake*

- *food intake*

- *importance of taking medication, e.g. for high blood pressure*

- *role of each team member (doctor, different nurses, social worker, etc.)*

- *For nurses: checklist to verify knowledge and understanding of key information by patients*

- *this could be used for teaching a new patient (not do it all at once to avoid information overload, but do it in parts)*

- *it should also be used periodically with more experienced patients, to*

- *reinforce and review key points with them*

- *the check list could be part of the patient's information card*

- *For nurses: translation aids for common terms in other language (written charts) such as Spanish, Greek, Italian and Cantonese.*

- **Oral communication**

- *Information for patients on:*
 - Fluid management and dry weight, how it relates to blood pressure and blood pressure medication*
 - How to understand blood results, e.g. Hemoglobin*
 - Explain medication needs ex. EPREX, self-administration of sub-cutaneous medication*
- *For nurses: tools for interaction with patient and for validation; need to check that what needs to be understood by the patient is indeed understood*

- **Other materials**

- *Videos, posters, pictures, etc.*
- *Video and actual demonstration of how to take care of catheter*
- *Model of a kidney in three dimensions*

Question #2: After we explained about the planned Health Education Centres, we asked nurses what are their in-service training needs as educators.

- *Access to resources for video production*
- *Access to resources for the production of posters*
- *Issues of time, human resources, and financial costs to consider*
 - patient committee should give input, they know what works for them*
 - they should give direct input in the teaching, the material given out*
- *Training in simple communication*
 - how to use appropriate words/vocabulary*
 - guidelines for content (so nurses give out the same standard information)*
- *A place to find models ex. 3D kidney model*

Focus group with Dialysis patients

8 patients and 1 caregiver participated. This meeting involved a lot of preparation (meeting twice with the patient representative, drafting a plain language bilingual invitation, informing the nurse manager, inviting patients from the morning and afternoon cycles, arranging the meal with the dietitian, finding space). Because some patients got off the dialysis machine late and others had to leave early for their transport, time allocation was limited and we had to skip the last question. Three participants were blind and one had very weak eyesight. It was a challenge for them to find a seat, eat, sign the consent form and follow the discussion.

Question #1: What kind of information do you need to know and learn to take good care of your health?

- *Information about diet, especially for a patient who is both diabetic and on dialysis.*
- *Proper diet for a small stomach (because of surgery).*
- *To see doctor more often, would like to know if there is hope for a future without dialysis.*
- *To know where to go in my area or neighbourhood for information on other health issues, such as diabetes.*
- *Information on how dialysis interacts with other illness.*
- *General information for ALL new patients.*
- *More consistent information from doctors and nurses. Sometimes, patients get different opinions from different doctors. One patient said: "We feel like yo-yos".*
- *Information to go the other way, from the patient to the nurse. Nurses need to listen more carefully to patients and respect what patients want. For example, one patient asked well in advance to have dialysis while seated, and this was not respected. Nurses need to read charts. They should not get offended and defensive when a patient says that the information is in the chart.*

We then presented what the nurses had said about what should be produced for patients (please see results of the focus group with dialysis nurses). We asked patients what they thought about it. They agreed with everything the nurses said and added the following:

- *Information on nutrition: there should be a general chart for all, but it needs to recognize that each patient has specific dietary needs.*
- *Information for new patients:
information should be for families also
all the information listed by nurses could be on a video to show new patients and their families, then have a group discussion and go over the main points*
- *For new patients, set up a buddy system, bringing together an experienced patient and a new patient; this idea was proposed in the past but was never implemented.*
- *About blood results, there is a need to really teach patients about this!*
- *About medication needs, there is a need to explain and demonstrate.*

Question #2: How do you like to learn?

Five choices were presented and patients were asked to say if they like to learn that way. Patients were told that they could add other ways to learn if they wished. Nobody did. The number identifies how many patients indicated each way of learning.

Read written information like pamphlets: 0 (4 out of 8 patients are blind or near blind)

Watch and listen to a video: 2 (again, 4 patients cannot watch a video)

Have someone explain one-to-one or in a small group: 4

Participate in a group discussion with other patients: 5

Find information on a computer (CD ROM or Internet) with a helper: 0 (the same 4 patients cannot use a computer)

Oncology Hematology Unit Focus group with patients

Six patients participated in this group (another 2 participated in the caregivers' group). There was some disruption as two patients either left early or arrived late because of appointments with doctors.

Question #1: What kind of information do you need to know and learn to take good care of your health?

- I need help after hours; I need to be able to access good medical services before 9am, after 5pm, on weekends and during holidays.

-I need to learn about my health after chemotherapy, what to do to stay healthy after my treatment.

-I need information about diet, more precise information about nutrition.

-I need to know how to help my family deal with my illness.

-I need information about medically approved alternative treatments to chemotherapy.

-I need information about what to do about combined drugs. For example, if you have a sinus infection and your regular doctor recommends Tylenol or prescribes antibiotics. Is this appropriate when following a cancer treatment? Which doctor should decide?

Question #2: How do you like to learn?

Five choices were presented and patients were asked to say if they like to learn that way. Patients were told that they could add other ways to learn if they wished. Here too, nobody did. The number identifies how many patients indicated each way of learning.

Read written information like handouts and pamphlets: 3

Watch and listen to a video: 2

Listen to a teacher explaining one-to-one or in a small group: 3

Participate in a group discussion with other patients: 3

Find health information on a computer with a helper: 1

Question #3: After explaining about the Health Education Centre, we asked what participants would like to find there? How can we make it interesting and attractive for them?

The results of a brainstorm were:

-Comments about Gilda's Club:

*this place can be "hard" for some patients, a lot of personal questions are asked
 some patients do not want to share information with other people who have cancer*

-Information about how to recognize symptoms, how to know that something is not right such as fever, infection, etc.

-A place for prevention, for example screening for colon cancer as is done for breast cancer

-Professionals must be giving out the information so patients are secure and know that the information is valid

-More written information on specific kinds of cancer

-Information on alternative forms of care, especially post-treatment care

-Show different videos once a week on different kinds of cancer; promote the showing among patients.

Focus group with Oncology Hematology caregivers

7 caregivers and 2 patients participated. Because of the difficulty of planning a focus group for caregivers at the outpatient clinic, we approached the 17th floor that serves Oncology Hematology in-patients. We said that patients were also welcome.

Question #1 What kind of information do you and your ___ (family member, son or spouse or...) need to know and learn to take good care of the patient's health?

- *To know more about the health services/support groups in my community and the health services/support groups in the area where my son lives.*
- *To know more about nutrition in a medical context. Which foods are the best? E.g., iron-rich foods.*
- *To know which physical activities are the best.*
- *To have medical information on my son's kind of cancer. I want to know the results of research done about this kind of cancer.*

Question #2 How do you or your ___ (family member, son or spouse or...) like to learn?

Five choices were presented and caregivers were asked to say if they like to learn that way. They were told that they could add other ways to learn if they wished. Again, nobody did. The number indicates how many caregivers chose each way of learning.

Read written information like handouts and pamphlets: 4

Watch and listen to a video: 4

Listen to a teacher explaining one-to-one or in a small group: 3

Participate in a group discussion with other patients: 0

Find health information on a computer with a helper: 2

Question #3 After explaining about the Health Education Centre, we asked what would caregivers like to find there? How can we make it interesting and attractive for them?

The results of a brainstorm were:

- *Convenient location, close to treatment*
- *Information should come from specialized nurses (but we do not expect them to know everything about all the types of cancer)*
- *Videos to see on how families can cope, dealing with the illness from a moral viewpoint*
- *A place to find pamphlets about Multimedia (type of cancer). This cancer is rare and it is very difficult to get copies of this pamphlet for family, friends, etc.*
- *One couple (parents of patient) added some comments in private, after the focus group. They said that doctors give out very little information and that as caregivers, they do not ask nurses too many questions because nurses are so busy. More human resources should be allocated to patient and family education. This should be a top priority of the health care system.*

Focus group with Oncology Hematology health care workers

7 nurses participated.

Question #1 What are the needs of health care professionals who inform and teach hard-to-reach patients?

We presented what three colleagues from the same clinic had contributed during individual interviews, and asked participants to validate and add to what had been said.

What colleagues had said:

1. More written information

Improve what is given out. In one booklet about the side-effects of chemotherapy, all the "scary" points of information are in bold.

Need for better-written handouts and pamphlets: attractive, good design, in plain language, with large letters, etc.

Some handouts should be translated into Italian and Greek
Nurses agreed with this and added Cantonese as a language.

2. More time and better space for oral communication/teaching
Need for more quiet, appropriate space for teaching. A quiet big room reserved for teaching would be great.
Nurses agreed with this.

3. Other tools
Videos to lend to patients (in English, in French and in other languages).
More time and space to show videos at the clinic.
Good posters, audio tapes.
Nurses agreed with this.

Participants added the following points:

A (*) before a paragraph indicates that the consultant has formulated sentences using the notes taken on a flip chart during the focus group.

**There are some tensions between the oncology nurses and the unit pharmacists who give out information in an environment not conducive to good teaching. They tend to emphasize all the negative side-effects of medication which is very scary for patients. The information is often not balanced, and is given too quickly, without enough explanation. According to these informants, the way pharmacists provide information does not complement what nurses are trying to achieve as educators. They identified a need to discuss this issue with pharmacists and find an agreement in a way that maximizes patients' learning.*

**Nurses emphasized the issue of patients being too anxious for learning. A lot of the teaching is done on the first day of treatment when patients are generally not in a good frame of mind for learning. There is also the problem of information overload. They meet too many different health care professionals who give out a lot of information on that same first day. An improvement might be to have patients come a week or 10 days before their first treatment for the teaching, as they should be less anxious. Another improvement would be to have a primary nurse assigned to each patient. This would allow better follow-up by that nurse (e.g., the nurse could call the day after the treatment to check that all is well and that the patient has understood key points). These strategies to improve patient education are being discussed but have not yet been implemented.*

**Nurses noted the challenges of validation, how to make sure the patient has indeed understood all that he or she needs to understand.*

** Videos could be shown in the family room (need for a mobile VCR).*

Participants added other points about the information and education needs of patients:

** All hard-to-reach patients, especially seniors who live alone, need to have a family member come with them to the clinic, in order to increase the effectiveness of teaching. However, the presence of a caregiver does not necessarily resolve everything as they sometimes screen what is said and what the patient needs to know. Also, nurses must not take anything for granted regarding caregivers, e.g. that a daughter trained as a nurse will know what to do.*

-Computer-literate patients need guidance as to what they find on the Internet (quality of information, relevance to their type of cancer). They often find inappropriate information.

-Patients need follow-up after their treatment; they should see a nurse.

-There is a need for more information/education related to prevention. There should be more written prevention pamphlets in the waiting room (Nurses pointed out that caregivers are often at a higher risk because they already have a family member with cancer.)

Nurses added that sick doctors are in fact hard-to-reach patients, since they think they know what to do.

Question #2 After we explained about the planned Health Education Centres, we asked nurses what were their in-service training needs as educators.

We proposed some and asked them to validate and add other needs.

We proposed:

- Need to know/understand more what it is like to be a hard-to-reach patient.
- Need to know how to identify low-literate patients.
- Need to know how to teach hard-to-reach patients: how to communicate more effectively with them (oral plain language).
- Need to know how to evaluate the effectiveness of teaching hard-to-reach patients.

Nurses agreed with these and added the following needs:

- How to evaluate the effectiveness of teaching with patients in general (at least for the highlights). This can become a legal issue; there is a need to protect health care professionals.*
- How to know that you are facing a patient with information overload. Nurses must NOT assume that all is well after the first treatment.*
- Learn more about health literacy issues of senior patients: the impact of learning problems, memory loss, weak health in general etc. on learning.*

Question #3 How can we set up the Health Education Centre for participants and their families? How can we make it interesting and attractive for them?

Some points were proposed. Nurses reacted to them and added more points.

We proposed:

- On site (while waiting)
- Drop-in
- Very welcoming and user-friendly
- Need to have good strategies to attract hard-to-reach patients and families
- Multiple means used to inform and teach such as plain-language written materials, videos, one-to-one and small group « classes », patient discussion groups, Computer programs (maybe), etc.
- Should have health care professionals and volunteers working in it

Nurses agreed with all the points, except one.

**They did not agree that the Education Centre should be a drop-in. They said that we have to find a way to make going to the Education Centre mandatory, at least for the first visit. It should be a natural part of all that patients go through at the clinic: see the doctor, get a blood test done, see the pharmacist, get your treatment, go to the Education Centre. It should be mandatory for both patients and family members.*

- Nurses noted that those naturally attracted by such a Centre would not be hard-to-reach patients. That is why the strategies to attract them will play a crucial role.*
- There should be ongoing evaluation of the effectiveness of the multiple means of informing and teaching hard-to-reach patients.*

SUGGESTION: *We should look into what the Radiotherapy clinic is currently doing as a model. A multi-disciplinary team of health care professionals provides general information for patients while planning the treatment.*

RECOMMENDATION: *The Education Centre would probably be in the family room.*

Focus group: Practice and Quality Improvement Council (PQIC)

We held a focus group with the PQIC Sub-Committee on Patient Education.

5 health care professionals and the nurses' librarian participated. The key question was: What are the needs of health care professionals who inform and teach hard-to-reach patients? We presented results from individual interviews and asked participants to comment and add (in italics).

Written Information

Upgrade teaching materials, the Pre-Op information sheets are a priority.

Write health information in plain language.

Produce material in other languages.

Produce material with better design, font, colours.

Material adapted for visually and hearing impaired.

Work on written documents must be done by professionals: technical writers in plain language, professionals translators, etc. Each professional does his or her task according to his or her expertise.

Maybe the Hospital Communication Department can take this on.

Oral Communication (teaching one-to-one and in groups)

More time and better space

Tips on how to communicate more effectively with hard-to-reach patients

Interpreters

« 1-800 » number for patients who have questions and need follow-up

Other Teaching Materials

Visual posters and videotapes to show and lend to patients

Posters must be done by professionals.

Use pictograms (internet sites offer good pictograms).

In each patient room, there should be a TV channel with health information, offering a choice of topic, illness, in different languages.

Training Needs

Not plain language writing, but plain language oral communication, how to use simple, concise oral communication.

How to identify hard-to-reach patients and assess what patients want to know.

How to be aware of different learning needs.

How to assess patient literacy, how patient learns best.

Learn through practical workshop and, role-playing.

We need to have a large spectrum of teaching tools, information pieces and ways to communicate with patients: written information, oral communication, videos, etc. in order to meet the different needs and learning styles of patients. We need to offer different versions of health information materials. Ex. for the patient, more pictorial, but for the family, more detailed written information. Ideally, we should have 4 or 5 different kinds of information and the educator could pick what is most appropriate to the needs of patient and family.

The first step is to update and re-write in plain language our written information. A hospital policy will not do it; each unit must work on it.